ALASKAN PHYSICIANS' KNOWLEDGE, ATTITUDES, AND BEHAVIORS RELATED TO FETAL ALCOHOL SPECTRUM DISORDERS

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Abstract

Fetal alcohol spectrum disorders (FASDs), caused by maternal consumption of alcohol during pregnancy, constitute the leading known preventable birth defects in the US. Given high prevalence rates and lifetime costs of FASDs in Alaska, it is imperative that healthcare providers have an adequate foundation of knowledge related to FASDs, as well as a strong sense of self-efficacy vis-à-vis their personal capacity to engage in primary and secondary prevention activities. The purpose of this study was to examine Alaskan physicians' self-reported levels of knowledge, attitudes, and practice behaviors related to FASDs, and identify effective ways to educate and train physicians about primary and secondary FASD prevention. Study goals were accomplished via an explanatory mixed methods research design involving three distinct phases; namely, a quantitative, qualitative, and application phase. Through study participation, Alaskan physicians shared their perceptions and opinions about systemic and professional barriers that affect educational and training needs related to FASD prevention and clinical intervention, as well as challenges that impede access to care for individuals who are affected by FASDs. Results based on surveys from 243 physicians and interviews with 24 key informants revealed that physicians are generally knowledgeable about the risks of alcohol consumption during pregnancy. However, physicians are in need of support to provide effective services related to FASD prevention and intervention. These needs include: 1) specialized education during medical school and residency; 2) easily accessible continuing education opportunities; 3) development and dissemination of best

practice protocols related to FASD care; 4) workforce development to increase referral options for patients; and 5) changes to healthcare systems to support primary and secondary prevention practices. Clearly, many challenges and obstacles identified by physicians are beyond their control and need to be addressed not only as independent practice issues but as larger medical education and healthcare systems issues. Given these realities and findings, the study concludes with suggestions and resources for physicians related to needed changes in FASD-related practice behaviors, as well as recommendations about how universities, medical schools, healthcare systems, and State and federal entities can better support physicians' efforts to reduce and treat these entirely preventable birth defects.

Table of Contents

Page

Page

Page

Page

Page

Page

Page

List of Figures

Page

List of Tables

Page

Page

List of Appendices

Page

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Chapter 1 Introduction

Brief Overview of the Study

Fetal alcohol spectrum disorders (FASDs), caused by maternal consumption of alcohol during pregnancy, constitute the leading known preventable birth defect in the US. Given high prevalence rates and lifetime costs of FASDs in Alaska, it is imperative that Alaska healthcare providers have an adequate foundation of knowledge related to FASDs, as well as a strong sense of self-efficacy vis-à-vis their personal capacity to engage in primary and secondary prevention activities. Given their emphasis on primary care, physicians are in a unique position to screen women for alcohol use during and prior to pregnancy, educate them about the dangers of prenatal alcohol exposure for the fetus, and coordinate care for women at risk of giving birth to an affected child. Further, physicians are in a position to educate women about relevant services in Alaska, such as FASD education, prevention, screening, diagnosis, referral, and treatment. For these reasons and others, physicians need to be knowledgeable about the effects of women's alcohol consumption during pregnancy and breastfeeding and need to develop the capacity and willingness to communicate information regarding the effects of maternal alcohol consumption to their patients. This study examined Alaskan physicians' level of knowledge, attitudes, and practice behaviors related to FASD to identify effective ways to educate and train physicians about FASD primary and secondary prevention.

Using a mixed methods research approach, this study sought to gain a comprehensive understanding of physicians' viewpoints about FASDs. Through

elaboration, convergence, and corroboration of findings from quantitative and qualitative methods, this study provides a broader and more complete range of data than would have been available through the use of either quantitative or qualitative methods alone (Johnson & Onwuegbuzie, 2004). Integrating quantitative and qualitative methodologies is commensurate with recent growth in the acceptance of qualitative research in the healthcare field (O'Cathain, Murphy, & Nicholl, 2007). The increased depth and breadth of information derived from a combination of quantitative and qualitative data serves as a strong basis of evidence for drawing meaningful and valid conclusions from the study, conclusions that provide significant guidance for developing purposeful recommendations toward improving FASD primary and secondary prevention practices by Alaskan physicians.

Significance of the Study

As medical science has become able to pinpoint specifically the prenatal effects of maternal alcohol consumption and make clear recommendations regarding abstinence from alcohol during pregnancy, medical providers and researchers have developed FASD guidelines for diagnosis and referral and have created core competencies for medical professionals (Stratton, Howe, & Battaglia, 1996). Despite these guidelines and role definitions, it is not known whether practicing medical care providers endorse these roles and practices as outlined for them by these guidelines. Indeed, few studies have been published that explore physicians' knowledge and attitudes about FASDs and their perceptions as to their roles and responsibilities in engaging in FASD primary and

secondary prevention. This study begins to fill this gap in the literature.

Problem Statement of the Study

Although physicians are in a unique position to educate pregnant women and women of child-bearing age about FASDs, little is known about the degree to which physicians take advantage of this opportunity. Indeed, little is known about physicians' level of knowledge, attitudes, and practice behaviors related to FASDs. The Centers for Disease Control and Prevention (CDC) FASD Regional Training Centers (FASD RTCs) outlined several roles for physicians and allied health professionals with regard to FASD primary and secondary prevention (FASD Regional Training Centers Curriculum Development Team, 2009). Specifically, the following roles were suggested for physicians: identifying and intervening with women at risk for an alcohol-exposed pregnancy; providing appropriate prevention services and substance abuse treatment referrals; screening and diagnosing individuals for FASDs; and supporting long-term care (e.g., case management) for individuals with FASDs (Sharpe et al., 2004). In alignment with these roles outlined by the FASD RTCs, this study sought to:

1) identify and contextualize FASD knowledge among Alaskan physicians;
2) assess and contextualize attitudes and beliefs about the role of Alaskan physicians vis-à-vis FASD primary and secondary prevention;
3) explore and contextualize Alaskan physicians' past experience and current practices as related to FASD; and
4) use empirical data to develop tailored recommendations for optimal FASD

primary and secondary prevention practices (including, but not limited to screening, diagnosis, referral, and treatment) among Alaskan physicians.

The quantitative and qualitative data derived through this study provide a foundation for developing competency-based protocols for FASD primary and secondary prevention within the unique systems of care in Alaska, with specific focus on Alaskan physicians. Special consideration was given to addressing possible mediating or moderating influences of professional background; professional experience; personal characteristics; and level of knowledge, attitudes, beliefs, and behaviors related to FASDs.

The ultimate goal for this study was accomplished in a research process involving three distinct phases. In Phase One, the study utilized an existing quantitative database to explore knowledge, attitudes, beliefs, and behaviors of Alaskan physicians as related to FASDs. The specific research questions that were explored in this phase are shown in Table 1.

Table 1

Quantitative and Qualitative Research Questions

Research Phase	*Questions or Domains of Interest*
Phase One: Quantitative Methods	1. What are physicians' levels of knowledge about FASD risk and how it is related to their personal, professional, and practice-related characteristics? 2. What are the relationships of physicians' levels of knowledge, attitudes, beliefs, and behaviors related to FASD and their: a. professional background b. professional experience c. practice location d. practice setting 3. What are the relationships of physicians' perceptions of their patients' access to FASD-related resources and their: a. professional background b. professional experience c. practice location d. practice setting
Phase Two: Qualitative Methods	1. What are physicians' perceptions of FASD in Alaska? 2. What approaches and techniques do physicians use to discuss the consequences of alcohol consumption during pregnancy with their patients? 3. What are systemic and professional barriers to FASD primary and secondary prevention (i.e., alcohol use screening, referral, diagnosis and treatment, and coordination of care) for Alaskan physicians? 4. What are facilitators and helpful strategies for FASD primary and secondary prevention (i.e., alcohol use screening, referral, diagnosis and treatment, and coordination of care) for Alaskan physicians? 5. What are the educational and training needs of Alaskan physicians as related to primary and secondary FASD prevention? 6. What service gaps and accessibility challenges do physicians perceive in Alaska as related to FASD?

In Phase Two, based on the quantitative data-derived information, qualitative data were collected that contextualized quantitative findings for a better understanding of physician-perceived barriers and challenges to proactive FASD primary and secondary

prevention, and physician-desired ways of enhancing medical education and self-efficacy about FASD primary and secondary prevention, diagnosis, and treatment. Specific research questions for this phase of the study are shown in Table 1. In Phase Three, combining information from Phases One and Two, a plan was developed for effective awareness-raising and education efforts targeted at Alaskan physicians to increase their knowledge, enhance their attitudes, and improve their practice behaviors as related to FASD primary and secondary prevention, diagnosis, and treatment.

Chapter 2 Review of the Literature

Introduction to Fetal Alcohol Spectrum Disorders

Fetal alcohol spectrum disorders (FASDs), caused by maternal consumption of alcohol during pregnancy, constitute the leading known preventable birth defect in the US. FASDs refer to "the full range, from mild to severe, of disturbances of physical, behavioral, emotional, or social functioning attributable to in utero alcohol damage" (Streissguth & O'Malley, 2000, p. 178). The term FASDs is the current nomenclature for such disturbances and encompasses, as well as supersedes, previously used terms, such as Fetal Alcohol Syndrome (FAS), Fetal Alcohol Effects (FAE), Alcohol-Related Birth Defects (ARBD), Alcohol-Related Effects (ARE), Partial Fetal Alcohol Syndrome (PFAS), and Alcohol-Related Neurodevelopmental Disorder (ARND). For purpose of this review, the term FASDs will be used to represent the full array of disorders caused by prenatal exposure to alcohol; the term FAS will be used to refer only to individuals meeting diagnostic criteria for the full syndrome.

FASDs are birth defects that have their primary effects on the brain. Although individuals neither outgrow FASDs nor are cured of FASDs, manifestations of the array of disorders may change with age and can be successfully managed with appropriate treatment and care. The following systems and realms of functioning can be affected by prenatal exposure to alcohol:

- physical and neuromotor functioning;
- sensory processing and integration;

- executive functioning and attention;
- learning and memory;
- speech and language; and
- psychosocial, behavioral, and adaptive functioning.

Many FASD symptoms are based in structural changes or malformations that occur during early gestation, the most likely period during which a woman might be unaware that she is pregnant (Astley & Clarren, 1999; Bonthius et al., 1996). Other FASD symptoms are related to damage to the central nervous system and result in functional (but not structural) disturbances. With regard to structural damage, most of the alcohol-induced damage in the fetal brain is caused by maladaptive growth of brain tissue, resulting in undeveloped or underdeveloped areas of the brain in which connections between neurons are improperly formed. The most vulnerable time period for the embryo in terms of effects of alcohol exposure is shortly after conception. Between four to eight weeks after conception, a transitory period from the embryonic to the fetal stage is a critical period, one that represents a time of great vulnerability to the toxic effects of alcohol (Caleekal, 2004). However, alcohol also affects the pre-embryonic or blastocyst stage, resulting in delayed implantation and structural changes in the embryo. Functional deficits, such as CNS damage, are usually produced at levels of alcohol exposure lower than those that would cause structural changes.

Several factors combine to determine the extent to which a child exposed to alcohol *in utero* will evidence FASD symptoms. Specifically, damage caused by prenatal

alcohol exposure depends upon how much alcohol is consumed; at what stage in pregnancy alcohol is consumed; and individual, genetic, nutritional, and metabolic factors of the mother and fetus (Maier & West, 2001). Alcohol consumed by a pregnant woman goes directly to the fetus at the same level of concentration as experienced by the woman. That is, for example, if the mother's blood alcohol level is 0.15, so is the fetus's. Maier and West (2001) explain that pregnant women have a body mass significantly larger than fetuses and a mature liver that can detoxify alcohol; however, a fetus's liver is smaller and immature and does not have equivalent detoxification capacity. For this reason, binge drinking, defined as consuming two or more drinks per hour, is more detrimental to the developing fetus than lower level, chronic drinking. Not surprisingly, given these data, consensus has emerged in the healthcare literature that no amount of alcohol can be safely consumed during pregnancy (FASD Regional Training Centers Curriculum Development Team, 2009).

Prevalence of FASD

Prevalence rates have been reported, but vary widely, for FAS and other prenatal alcohol-related conditions. May and Gossage (2001), summarizing research since the late 1970s to determine overall prevalence rates in the US, estimated that FAS prevalence in the general population of the US is between 0.5 and 2 per 1,000 live births. The National Center on Birth Defects and Developmental Disabilities (NCBDDD, 2010) at the CDC has acknowledged wide variation in FAS prevalence rates depending on population studied and surveillance methods used. Recent FAS prevalence rates range

from 0.3 to 1.5 per 1,000 live births (NCBDDD, 2010). In Alaska, population incidence rate was 1.5 per 1,000 live births between 1995 and 1997 (CDC, 2002), approximately four times higher than rates in Arizona, Colorado, and New York, other states in the CDC FAS Surveillance Network (CDC, 2002). These findings equate to approximately 15 Alaskan infants born each year meeting full FAS criteria. More recently, a trend analysis conducted by the State of Alaska Maternal Child Health Epidemiology Unit revealed a decrease in FAS rates from 19.9 to 13.5 per 10,000 live births (Schoellhorn, 2010). This decline was limited only to Alaska Native FAS birth rates, as the prevalence of non-Native FAS birth rates increased.

Prevalence rates for other prenatal alcohol-related conditions in the US (i.e., FASDs other than FAS) are estimated by the CDC (2002) at three times the national rate for FAS, namely, approximately 4.5 per 1,000 live births. May and Gossage (2001), on the other hand, in considering the full spectrum of disorders, estimated a higher U.S. prevalence rate of 10 per 1,000 or 1% of all live births. For Alaska, Surveillance Network findings suggest a rate of 16.3 per 1,000 live births affected by prenatal alcohol exposure for the years between 1995 and 1997 (CDC, 2002), over 10 times the Alaska FAS rate.

Cost of FASD

As the leading known preventable cause of mental retardation in the US. FAS has been researched as to its economic impact. Not surprisingly, researchers for the U.S. Department of Health and Human Services identified the need to address the cost of FAS

due to a high level of public and research-related interest in FAS as a preventable medical condition (National Institute on Alcohol Abuse and Alcoholism [NIAAA], 2000). To date, most cost studies have focused on the full syndrome (fetal alcohol syndrome) rather than the continuum of FASDs; hence, FAS is of focus here. Estimates of the cost of FAS vary greatly depending on several factors, including incidence rates, methodologies used for cost analysis, and data sources (Abel & Sokol, 1991; Bloss, 1994; Harwood & Napolitano, 1985; Podolsky, 1984). In addition, cost categories of interest have varied, with some analyses focusing on annual national healthcare costs and productivity costs, and others including societal and individual lifetime costs. Given variations and challenges in cost estimation, the issue of FAS- and FASD-related costs is far from settled, especially at the State level.

Nonetheless, from a national perspective, cost estimates have been calculated related to healthcare, productivity, and societal cost. Estimated overall cost of FAS to society appears to vary widely according to study, from $1.9 to $9.69 billion (Harwood & Napolitano, 1985; NIAAA, 2000; National Institute on Drug Abuse, 1998). One national annual cost estimate is $2.8 billion, encompassing expenses related to healthcare and anticipated productivity losses (NIAAA, 2000). Interestingly, 90% of the $2.8 billion was spent on providing residential and home care for adults and special education services for children and adolescents. Not quite as discrepant as overall societal costs, lifetime costs to affected individuals and their families have ranged from an estimated $596,000 per person per lifetime to $1 million per person per lifetime (Abel & Sokol,

1991; Harwood & Napolitano, 1985). With regard to Alaska-specific costs, the only existing cost study was conducted by the McDowell Group (2001), which estimated costs for FAS births for 1999 based on 14 FAS births and found the lifetime economic cost for these individuals to the State of Alaska totaled approximately $21 million.

Diagnostic Process of FASD

Rendering an FASD diagnosis, as explained by Stratton et al. (1996), serves several major purposes, including "to facilitate communication among clinicians; to facilitate communication between clinician and patient (including, in this instance, the parents of patients); to assist in the study of pathophysiology and etiology; and to guide treatment" (p. 2). Concerns exist regarding potential stigma associated with FASD diagnoses and possible negative lifelong implications of "labeling" an individual with organic brain damage. However, benefits of comprehensive and accurate diagnosis are believed to outweigh possible drawbacks. Specifically, the primary advantages of making accurate diagnoses are: 1) improved long-term treatment outcomes for individuals with FASD and their families; 2) reduced risk of secondary disabilities for affected individuals who were diagnosed early in life; 3) identification of mothers in need of education and counseling for the purpose of preventing FASD in future children; and 4) encouragement of caregivers to seek diagnosis and support for previously undiagnosed siblings.

Although making an official FASD diagnosis is under the sole purview of a physician, an FASD diagnosis is in actuality a process that involves multiple assessments

and professionals from diverse disciplines. Many areas of functioning are evaluated in a comprehensive FASD diagnosis, including learning and cognition, speech and language, attention and executive functioning, memory and visual-spatial skills, sensory and motor skills, behavioral and emotional adjustment, and adaptive skills. Such diverse assessments are typically accomplished by a multidisciplinary team of experts that may include a physician (especially with a specialization in pediatrics or family practice), psychologist, speech and language pathologist, social worker, occupational rehabilitation therapist, and mental health clinician. Such a team is often utilized to gather individual test data and then compile and integrate results into an overall diagnostic picture.

How exactly a team of experts goes about making an assessment and diagnosis is driven to a large degree by the diagnostic paradigm under which they function. Currently, several diagnostic paradigms (and commensurate procedures) exist for the derivation of an FASD diagnosis. In comparing diagnostic systems used across the US, primary differences emerge not in terms of criteria used for diagnosis, but rather, in terms of how criteria are applied procedurally (e.g., quantitative vs. qualitative measurement scales, multidisciplinary vs. individual discipline, active vs. passive prevalence ascertainment, screening vs. clinic-based diagnosis). Most methods evaluate four distinct diagnostic domains to establish a diagnosis; namely, growth deficiency, facial phenotype, brain dysfunction, and gestational alcohol exposure. Definitions and examples for each of these areas are provided in Table 2; additional details are provided below.

Table 2

Definitions and Examples for the Four FASD Diagnostic Domains

Diagnostic Domain	*Definition*	*Examples of Symptoms*
Facial Phenotype	1. Small palpebral fissure lengths (2 or more standard deviations below the mean) 2. Smooth Philtrum 3. Thin upper lip	• Impaired visual acuity (i.e., nearsightedness) • Central and peripheral hearing deficits • Optic nerve hypoplasia
Growth Deficiencies	1. Height < 10th percentile 2. Weight < 10th percentile	• Medically fragile • Heart, kidney, and digestive problems • Poor muscle tone • Ongoing need for medical care (i.e., poor eyesight, fragile bones, and increased number of illnesses)
Brain Dysfunction	1. Structural abnormalities 2. Neurological abnormalities 3. Functional Central Nervous System abnormalities	• Static encephalopathy • Microcephaly • Impairment in brain functions, such as cognition, achievement, memory, executive functioning, motor, language, attention, and activity level
Gestational Alcohol Exposure	1. Biological mother consumes alcohol during pregnancy (anytime following conception through the nine-month gestational period)	• Alcohol use during pregnancy is confirmed

Use of these four diagnostic domains is the basis for two primary diagnostic methods referred to most commonly in the literature: the University of Washington Four-

Digit Code (Astley & Clarren, 1999) and the Institute of Medicine (IOM) FAS Diagnostic Criteria (Stratton et al., 1996). The University of Washington FAS Diagnostic Prevention Network method employs a four-digit diagnostic code, reflecting magnitude of expression of potentially FAS-related symptoms and strength of evidence to support the presence of an organic cause for brain dysfunction. For each assessed individual, a separate single-digit code is determined for each of the four areas of assessment, namely, growth deficiency, facial phenotype, gestational alcohol exposure, and brain dysfunction.

IOM's guidelines for diagnostic and clinical evaluation of FAS were developed by a committee of experts assembled to review and revise existing FAS diagnostic criteria. IOM's diagnostic process is based on gathering information within four key areas: maternal alcohol exposure; characteristic pattern of facial anomalies; growth retardation; and central nervous system neurodevelopmental abnormalities, including a complex pattern of behavioral or cognitive deficiencies.

Manifestation of FASDs

FASDs have been broadly characterized by pre- and postnatal growth deficiency; characteristic set of minor facial anomalies; and evidence of prenatal alteration in brain function, such as microcephaly from birth, neurological problems without postnatal antecedents, or complex patterns of functional disability (Astley & Clarren, 1999). FASDs are an umbrella term describing the range of effects that can occur in an individual who is exposed to alcohol *in utero*. As described earlier, this spectrum of

disorders can include FAS, Alcohol-Related Neurodevelopmental Disorder (ARND), and Alcohol-Related Birth Defects (ARBD).

With regard to FAS, the physiological presentation lies at the extreme end of the continuum of alcohol effects on the fetus and fully meets all diagnostic criteria (growth deficiency, facial anomalies, CNS damage, and prenatal alcohol exposure). FAS is often referred to as the tip of the iceberg of prenatal alcohol effects. According to Streissguth and Kanter (1997), full FAS comprises only about 10% of the fetal alcohol spectrum. The other 90% of children with FASDs may have fewer or no visible physical symptoms, yet exhibit significant structural and functional abnormalities in the brain. The most important manifestations of FASDs are facial features and growth deficiencies, neurological impairment, and neurobehavioral manifestations. Another important aspect of FASDs is the presence (or absence) of secondary disabilities, that is, disabilities that may accompany FASDs or may result from symptoms of FASDs. These four aspects of FASDs are addressed in detail below.

Facial features and growth deficiencies. The typical clinical syndrome of FAS contains facial anomalies, including overall flattening of the middle portion of the face. This is also true in varying degrees for children who do not meet the full FAS criteria, but fall somewhere on the FASD spectrum. More specifically, children may evidence:

a) epicanthal folds (extra skin folds coming down around the inner angle of the eye);

b) short palpebral fissures (small eye openings);

c) a flattened or elongated philtrum (no groove or crease running from the bottom of the nose to the top of the lip);

d) thin upper lips;

e) small mouth with high arched palate (roof of the mouth);

f) small teeth with poor enamel coating; and

g) low-set ears.

The characteristic facial features outlined above vary in severity, depending upon multiple variables, and may not be apparent to most people. Practitioners who regularly work with children experiencing prenatal exposure to alcohol are often able to recognize the distinct and more subtle facial features. However, an FASD diagnosis can only be made reliably by a physician properly trained in the identification of these symptoms.

In addition to having distinct facial features, children or adults with FAS and FASDs may have a variety of malformations of major organs, especially the heart and kidneys, as well as eyes and ears (Astley & Clarren, 1999). Many children with FAS have vision problems, with a good number of them having an eye that turns inward (sometimes referred to as "lazy" eye). Additionally, children with FAS often have a predisposition to ear infections and a high rate of hearing loss (eighth nerve deafness), making a thorough hearing exam necessary to rule out these complications.

Neurological symptoms and manifestations of FASD. Prenatal exposure to alcohol may have profound effects on the developing fetus, resulting in numerous neurological symptoms. Following is a description of these effects within four

categories: neuromotor, sensory processing, and sensory integration; executive functioning and attention; learning and memory; and speech and language skills.

Neuromotor, sensory processing, and sensory integration. Prenatal exposure to alcohol contributes to significant deficits in motor control (Goodlett, Thomas, & West, 1991; Meyer, Kotch, & Riley, 1990). These deficits have been associated with problems related to the CNS, peripheral nervous system, and vestibular system. Impairments in neuromotor functioning are expressed as poor coordination, poor balance, and abnormal gait. Difficulties in sensory processing and sensory-motor integration are linked to CNS functioning. Morse and Cermak (1994) discovered that young children with FASDs experienced significantly more sensory processing problems (e.g., touch sensitivity, movement, taste, smell, visual and auditory stimuli, hyperactivity, disorganization, feeding and sleep difficulties) than children without FASDs.

Executive functioning and attention. Generally speaking, the term "executive functioning" applies to an individual's ability to perform specific cognitive functions, such as planning, organizing, sequencing, abstract thinking, and mental flexibility. Deficits in executive functioning among individuals with FASDs have been found for both cognition- and emotion-based actions. With regard to cognition-based executive functioning, individuals with FASDs experience impairment in their ability to develop and employ effective planning strategies, ability to shift from task to task without making errors due to increased perseveration (set shifting), ability to generate rapid verbal and non-verbal responses, and ability to solve new problems quickly and accurately

(Kodituwakku, May, Clericuzio, & Weers, 2001; Schonfeld, Mattson, Lang, Delis, & Riley, 2001). The most consistent findings related to impairments in executive functioning are mathematical and problem-solving difficulties (Kodituwakku et al., 2001; Mattson, Riley, Delis, Stern, & Jones, 1996).

A strong association has been reported between prenatal exposure to alcohol and difficulty in maintaining attention, even for children who have been exposed to relatively low levels of alcohol before birth. Among children and adolescents diagnosed with FASDs, six of 10 children and adolescents were found to have attention deficits (Nanson & Hiscock, 1990; Streissguth, Barr, Kogan, & Bookstein, 1996). Jacobson and Jacobson (2002) concluded that attention deficits occur primarily in the context of sustained attention tasks that require active recall of information or response inhibition, suggesting impairment in executive function rather than sustained attention *per se*. Korkman, Kettunen, and Autti-Ramo (2003) added that poor performance occurs on tests of "relative complexity and high attentional and working memory demands" (p. 123). Childhood impairment in executive functioning is considered to be a predictive factor for difficulties in behavior and adaptive functioning in later life (Nigg, 2000).

Learning and memory. Intellectual functioning of children with FASDs can vary from severe mental retardation to average intelligence. However, even children with FASDs who have average intellectual functioning may experience significant deficits in cognitive functioning (Streissguth et al., 1996). Children with prenatal alcohol exposure experience profound challenges in learning material presented verbally; however, they

are able to retain the information once they have learned it (Mattson et al., 1996). Mattson and colleagues (1996) discovered that alcohol-exposed children tend to offer extraneous answers and use repetition as a way of trying to remember words on a list.

Alcohol exposure is associated with slower and less efficient information processing (Jacobson, Jacobson, Sokol, Martier, & Ager, 1993). Children with prenatal alcohol exposure have been found to have impairments in their ability to perceive and remember spatial relationships and in recalling visual information (Mattson et al., 1996; Uecker & Nadel, 1996). In school functioning, achievement scores of children affected by FASDs often fell below their IQ scores (Streissguth et al., 1996), with most consistent academic deficits occurring in arithmetic functions (Streissguth & O'Malley, 2000).

Speech and language skills. Children's developmental delays in language acquisition and deficits in expressive and receptive language have been linked to *in utero* alcohol exposure (Carney & Chermak, 1991; Church & Kaltenbach, 1997). Church and Kaltenbach (1997) reported impairments in syntactic or grammatical abilities, semantic abilities, and memory. Coggins, Friet, and Morgan (1998) found impairments in social communication that manifest primarily as illogical judgment, lack of critical thinking, and poor social problem solving. Such social communication serves the purpose of exchanging information, developing social relationships, adapting to environmental changes, and expressing personal needs and desires. Thus, deficits in social communication have implications for all of these aspects of day-to-day functioning.

Neurobehavioral components of FASD. Individuals with FASDs are at a high

risk for social and psychological problems that disrupt school and home environments. More specifically, heavy prenatal alcohol exposure has been linked to high rates of anxiety, depression, attention problems, trouble with the law, alcohol and drug abuse, poor academic achievement, and poor social skills (Mattson & Riley, 2000; Roebuck, Mattson, & Riley, 1999). Many of these difficulties appear to be a result of impairments in executive functioning and, more specifically, the tendency for individuals with these deficits to act without considering the consequences of actions, to struggle with problem-solving tasks, and to experience difficulties in developing sequential plans to address problems (Mattson, Schonfeld, & Riley, 2001).

Areas of substantial neurobehavioral deficits include a notable lack of responsiveness to social cues and poor interpersonal relationships (Streissguth et al., 1991). Thomas, Kelly, Mattson, and Riley (1998) reported that children with FASDs exhibit social impairments in using manners and interacting appropriately with others. In school environments, teachers tend to rate children with prenatal alcohol exposure as less socially adept and more aggressive than children without prenatal alcohol exposure (Brown et al., 1991; Jacobson, Jacobson, Sokol, & Ager, 1998). Jacobson and Jacobson (2002) described children with FASDs as being "more likely to exhibit antisocial behaviors, lack consideration for the rights and feelings of others, and resist limits and requests by authority figures" (p. 285).

The range of challenging behaviors associated with FASDs varies from mild to severe, with some disabilities preventing the individual's ability to cope with even simple

day-to-day tasks. For many children, behavioral difficulties caused by the effects of prenatal alcohol exposure present the primary challenges to treatment and symptom management. Steinhausen, Williams, and Spohr (1993) described common social traits observed in children with FASDs, such as being talkative, affectionate, and outgoing. These children often exhibit an overly trusting, loving, and naïve demeanor despite their years. As a result of brain damage from prenatal alcohol exposure, children may have significant difficulty, especially as they mature, in evaluating situations and using past experiences to cope with present circumstances. As a result, they need more protection, supervision, and structure for a longer period of life than individuals without FASDs.

Secondary disabilities. As previously noted, early and accurate diagnosis of FASDs has the potential to prevent secondary disabilities. Secondary disabilities are defined as those not present at birth but occurring as a result of primary disabilities. They can presumably be prevented or lessened by better understanding and appropriate intervention (Streissguth et al., 1996). Children with FASDs tend to experience more severe secondary symptomotology than those with FAS, and are at significantly greater risk for developing secondary disabilities due to the "hidden" nature of their disorder, given less visually obvious facial features and growth deficiencies (Streissguth, 1997). One seminal study identified six main categories of significant secondary disabilities through life history interviews of 415 individuals with FASDs (Streissguth et al., 1996):

- mental health problems;
- disrupted school experience (suspension, expulsion, or drop out);

- trouble with the law (involvement with police, charged or convicted of crime);
- confinement (inpatient treatment for mental health, alcohol/drug problems, or incarceration for crime);
- inappropriate sexual behavior; and
- alcohol and drug problems.

As early and accurate diagnosis helps prevent secondary disabilities, it also reduces misdiagnosis that is based on symptom presentation stemming from the development of secondary disabilities. FASDs with secondary disabilities are often misdiagnosed as Attention Deficit Hyperactivity Disorder, Attention Deficit Disorder, Oppositional Defiant Disorder, Conduct Disorder, Reactive Attachment Disorder, Post Traumatic Stress Disorder, Cyclothymic Disorder, Autism, Mental Retardation, and Cognitive Disorder Not Otherwise Specified. Although some of these diagnoses may well *accompany* an FASD diagnosis, they do not account for the full constellation of behaviors that warrants a primary diagnosis of FASD. Therefore, the manifestations of secondary disabilities may actually result from FASDs that have gone undetected or misdiagnosed and, subsequently, are ineffectively and inappropriately treated.

Risk and protective factors. Research has identified known risk and protective factors affecting secondary disabilities. In other words, families and communities can take preventive actions to make a difference in the lives of children with FASDs as they mature and prevent or minimize the impacts of secondary disabilities. First and foremost, securing an FASD diagnosis early in life, before age six, has been described as a

powerful protective factor against the development of secondary disabilities (with the exception of mental health difficulties; Streissguth & Kanter, 1997). According to Streissguth and Kanter (1997), "diagnosis provides visibility and visibility prompts solutions" (p. 122). For example, Streissguth et al. (1996) identified eight universal protective factors that emerged from the data for individuals 12 years old and older. The eight universal protective factors included:

- living in a stable and nurturing home for over 72% of life;
- being diagnosed before the age of six years;
- never having experienced violence against oneself;
- staying in each living situation for an average of more that 2.8 years;
- experiencing a good quality home from age eight to 12 years;
- being found eligible for Developmental Disabilities services;
- having a diagnosis of FAS (physical features present); and
- having basic needs met.

Given the increase in understanding related to secondary disabilities, risk factors, and protective factors, special attention needs to be given to early and accurate diagnosis and implementation of treatment strategies that are effective for treating FASDs. Proactive work is particularly important for individuals with FASDs (rather than FAS) as they are at a higher risk for misdiagnosis. Many protective factors simply cannot be realized in the life of an affected child if a proper diagnosis is not made. Proper and early diagnosis is especially important given that individuals affected by prenatal exposure to

alcohol, regardless of whether they meet the criteria for FAS, are less likely to be able to live in a self-sustaining independent manner (Streissguth et al., 1991). As the diagnostic process plays a major role in long-term positive outcomes, it is vital to promote its importance with the primary group of healthcare providers who possess the medical credentials to render an accurate diagnosis, namely, physicians.

Postnatal Effect of Alcohol Use during Breastfeeding

Another area of concern related to alcohol exposure is alcohol exposure during the first year of life through breast milk. Although this issue is at time not considered part of the FASD spectrum (i.e., not included in prevention and intervention efforts related to FASDs), it is an issue that seems to arise in the context of care providers who deal with women of child-bearing age and who are using alcohol either socially or as a substance of abuse. Research investigating postnatal effects of alcohol exposure through breast milk is only just beginning to develop, but early findings compellingly suggest that alcohol in breast milk is associated with negative consequences for infants. Such negative consequences include decreased nutritional intake, altered sleep patterns, delayed motor functioning, and possible negative responses to future alcohol use. According to Mennella and Beauchamp's (1993) research, breast milk containing alcohol may negatively affect the nutritional intake of infants because it reduces the total amount of milk consumed. One theory to explain this finding is that alcohol, as a depressant, may have a sedative effect on infants who ingest it through breast milk, causing them to fall asleep and to have a less effective suckling response. Mennella and Beauchamp

(1993) also found that consuming breast milk containing alcohol altered infants' sleep-wake patterns beyond the time of nursing, resulting in a reduction in active sleep. A link between maternal drinking and delayed infant motor development has also been identified, caused by alcohol's interference with cell myelination (Lindmark, 1990). With regard to future vulnerability to alcohol addiction, concerns exist related to how the sensory qualities of alcohol in mother's milk might affect the child's responses to alcohol in the future (Mennella, 2001). Therefore, it may be just as important for medical providers to educate women on the *postnatal* effects of alcohol exposure through breast milk as it is to discuss prenatal effects.

Physicians and FASDs

Given the importance of early and accurate diagnosis, physicians are a primary target group for education about FASD detection, screening, and diagnosis. This is particularly critical as physicians are *the* professional group that can make a diagnosis and are most likely to have early contact with pregnant women or women of childbearing age. Physicians are in a unique position to educate pregnant women and women of childbearing age about FASD prevention. Through effective educational messages, medical doctors can create opportunities for patients to think about the consequences of alcohol consumption during pregnancy and contemplate the benefits of behavior change, actively engaging them in primary prevention. In addition to primary prevention, physicians can have a special role in the care of individuals who already have an FASD by recognizing, diagnosing, and treating FASDs as early in the lifespan as possible. Such

secondary prevention is crucial given the reality that early diagnosis serves as a protective factor for secondary disabilities among children with FASDs.

As physicians are the only providers with the credentials to diagnose disorders related to fetal alcohol exposure, their obligation for primary and secondary prevention goes beyond that of other general healthcare providers, and their level of competency must align with this duty. Medical providers who work regularly with women and children are often responsible for FASD care, especially providers in the specialty areas of obstetrics and gynecology, pediatrics, and family practice. Within the last decade, research has begun to focus on establishing a better understanding of these specialty physicians' education, training, and knowledge; perceptions, attitude, and beliefs; and practices related to general FASD primary and secondary prevention, including screening, diagnosis, intervention, referral, and care coordination.

Physician education and training about FASD. Current levels of education and training and current resources available to physicians related to FASD prevention, detection, diagnosis, and care have been identified as insufficient to prepare practitioners for providing effective and comprehensive medical and prevention services as related to FASDs. For example, one major venue for training and educating physicians is the use of textbooks. Loop and Nettleman (2002) reviewed obstetrical textbooks published over the past four decades to identify trends related to FASD education. Of 81 clinical obstetrical texts sampled, only 17% consistently recommended that pregnant women abstain from alcohol use during pregnancy (as recommended by the Institute of

Medicine, 1996). More recent texts published between 1990 and 2000 exhibited some improvement, with 24% recommending abstinence from alcohol during pregnancy. Most concerning was the finding that, of recent texts, 52% contained references to condoning some maternal alcohol consumption and 24% gave no clear recommendation one way or another. These findings suggest that FASD prevention is not adequately addressed and guidelines for diagnosis and treatment are virtually absent (if not erroneous) in the primary materials used to educate physicians.

As for medical school training related to FASDs, focus appears to be on the identification of clinical features of FASDs, with limited attention to practice guidelines related to primary and secondary FASD prevention. For example, Mengel and colleagues (2006), in a study of family physicians in the Midwestern U. S., found training about FASD clinical features was provided to respondents in medical schools and residencies 56% and 43% of the time, respectively. In contrast, training related to the care of children with FASDs was provided to respondents in medical schools and residencies only 36% and 48% of the time, respectively. Only 21% of respondents received training related to family support for children with FASDs. This study also found that physicians had concerns about the quality of their FASD-related training, with a majority (77% to 82%) of respondents rating their FASD education as fair or poor.

With regard to post-graduate education and training, physicians continue to struggle to acquire needed information to serve patients experiencing FASD. In 2003, Gahagan et al. (2006) surveyed members of the American Academy of Pediatrics (AAP),

receiving 879 responses from general pediatricians, pediatric specialists, and pediatric residents. Although 72% of participants reported receiving some form of post-graduate training about FASDs, only 28% were trained in the use of assessment instruments for screening and diagnosis and only 50% received training about how to screen for risky drinking behavior. More than half of the respondents reported not having any formal training about FASD treatment and management, community resources, effective communication, confidentiality issues, and alcohol cessation interviews.

Physician knowledge of FASD. Recent survey research suggests that physicians have basic foundational knowledge related to FASDs (Elliott, Payne, Haan & Bower, 2006; Gahagan et al., 2006; Mengel et al., 2006; Nanson, Bolaria, Snyder, Morse, & Weiner, 1995; Tough, Clarke, Hicks, & Clarren, 2005). Although knowledge appears to have improved over time, gaps in understanding remain and have an effect on medical practice. As illustrated in the AAP study mentioned above, pediatricians were found to have good general knowledge of FASDs' clinical presentations. Specifically, 80% of participants were able to identify clinical effects and 57% understood that early diagnosis was a protective factor. However, FASD prevention knowledge was less encouraging, with Gahagan et al. (2006) finding that 16% of respondents considered an occasional drink by a pregnant woman as safe and 87% never addressed the issue of alcohol use during pregnancy with adolescent female patients. Similarly, Anderson et al. (2010) found that 34% of surveyed obstetricians/gynecologists indicated that occasional alcohol consumption can be safe.

Similarly, Mengel et al. (2006) found that family physicians possess general knowledge of FASDs and understand that early diagnosis can improve outcomes. Despite this general understanding, studies suggest that physicians' level of competency varies related to the recognition of clinical features of FASDs. For example, significant deficits were revealed in physicians' ability to recognize and diagnose FASDs and to identify facial dysmorphology features associated with the full syndrome (Mengel et al., 2006). Additionally, findings from an Australian study of pediatricians corroborated this phenomenon. Elliott and colleagues (2006) found that only 19% of their sample was able to identify the four essential diagnostic features; however, this lack of ability did not translate into referrals to experts to make diagnoses. Instead, regardless of the accuracy of their diagnostic understanding, 49% of respondents reported rendering FASD diagnoses.

The lack of a comprehensive understanding of FASDs by physicians limits the opportunities for improved outcomes associated with primary and secondary prevention, diagnosis, and early intervention (Elliott et al., 2006). Barriers to providing competent FASD prevention, diagnosis, and treatment services (e.g., dearth and poor quality of training and educational materials; Gahagan et al., 2006; Mengel et al., 2006; Nanson et al., 1995) represent a missed opportunity of prevention by the very providers who have the potential for powerfully important and effective intervention with high-risk groups of patients. Of course, knowledge and training in and of themselves do not necessarily translate into action. Reviewing the general propensity of physicians for prevention

efforts is another important piece in the puzzle toward better understanding how to engage physicians in primary and secondary FASD prevention.

Physician FASD prevention efforts. The practice of prevention activities by physicians is of interest to a broad range of health fields, expanding beyond the public health issue of prenatal exposure to alcohol. By virtue of their position and function in healthcare, physicians are key in the delivery of preventive care. However, routine integration of primary prevention into practice has been sub-optimal, resulting in lost opportunities to address alcohol consumption during pregnancy (Gassman, 2003). From a general primary prevention perspective, Mirand, Beehler, Kuo, and Mahoney (2002) found that "physicians placed a high level of worth on primary prevention, including behavioral counseling, but its practice was negated by the predominant clinical emphasis on and rewards for secondary care" (p. 2). Physicians reported that key deterrents to primary prevention activities were lack of health behavior training, perceived low self-efficacy, and patient resistance to change.

Although physicians have a clear role in primary prevention of FASDs, research has found that they neither consistently screen for alcohol use during pregnancy nor address consequences of alcohol use during pregnancy. With regard to at-risk groups, the survey of AAP members (Gahagan et al., 2006) found most pediatricians were reluctant to address use of alcohol during pregnancy with women of child-bearing age. Of particular concern was the finding that only 13% of pediatricians reported counseling adolescent females about the dangers of alcohol consumption during pregnancy (Gahagan

et al., 2006). The same pattern was revealed for Australian pediatricians; only 23% of surveyed physicians routinely asked about alcohol use when taking a pregnancy history and a low 4% provided information to patients about prenatal alcohol exposure (Elliott et al., 2006). On the other hand, in a survey of OB/GYNs, Anderson et al. found that 82.2% of respondents asked about alcohol use during a patient's initial visit. However, such questioning about alcohol use was done in subsequent visits by only 10.6% of the respondents.

Prevention efforts may vary based on a woman's health status. For example, in a study of Canadian physicians, approximately 50% discussed alcohol use or addiction history with women of childbearing age; however, once a woman was pregnant, 95% of providers screened for alcohol consumption (Tough et al., 2005). In a similar study of Canadian family physicians, 75% counseled pregnant women and 61% counseled women of childbearing age; the most commonly used screening was to collect frequency and quantity of alcohol use (Nevin, Parshuram, Nulman, Koren, & Einarson, 2002).

Physician FASD diagnostic efforts. Although physicians acknowledge the existence of FASDs in their service populations, they appear hesitant to participate in the diagnostic process as part of their routine clinical practice. The percentage of physicians reporting that they have given a formal diagnosis of FASDs ranges from a low of 8% to a high of 49% (Elliott et al., 2006; Nevin et al., 2002). Interestingly, although physicians may not routinely conduct formalized FASD diagnostic services, they still report observing the disorder in their medical practices. Gahagan et al. (2006) found that over

50% of pediatricians reported having experience with children diagnosed with FAS, about 62% of pediatricians considered themselves prepared to identify FASDs, and 50% felt prepared to render a diagnosis.

A pattern of hesitancy has emerged related to physicians' willingness to render a diagnosis of FASDs. Elliott et al. (2006) found that 76% of pediatricians in their study had suspected, but not diagnosed; 12% were convinced of a diagnosis, but did not record it in the patient's medical record; and 31% referred to another provider to render a diagnosis. Another study reported that 17% of family practice physicians suspected FASDs, but did not diagnose them; and approximately 13% made a referral to seek a second opinion or confirm a diagnosis (Nevin et al., 2002). Across studies, physicians identified various reasons for not conducting diagnostic services related to FASDs, including, but not limited to, lack of FASD diagnostic training; insufficient time to devote to the diagnostic process; concerns over stigma associated with a diagnosis; and the belief that better qualified specialists were available to make a diagnosis (Elliott et al., 2006; Gahagan et al., 2006; Mengel et al., 2006).

Physician FASD treatment efforts. Understanding what is needed to care effectively for children with FASDs and their families is a difficult undertaking for physicians, partially because evidenced-based treatments for FASDs are still in their infancy in the medical and behavioral health fields. Unsurprisingly, past research suggests that physicians are uncertain as to how to approach long-term care related to FASDs and, more specifically, what it would mean to serve as the medical home for

individuals affected by an FASD. Gahagan et al. (2006) found that only 34% of sampled pediatricians felt prepared to manage and coordinate treatment needs of children diagnosed with FASDs. Another study found that only six of 132 pediatricians indicated they were very prepared to care for individuals with FASDs (Elliott et al., 2006).

Physicians' perceived barriers to FASD prevention, diagnosis, and care. Although physicians are in an opportune position to provide much-needed prevention, diagnostic, and treatment services for individuals with FASDs, most physicians struggle with rendering these services as a part of their routine medical practice. Many physicians feel ill-equipped when faced with patients who present with the multi-faceted and complex physical, neurological, psychological, and behavioral characteristics of FASDs. Thus, obstacles exist that interfere with physicians' ability and willingness to treat FASDs. These barriers are most salient in FASD prevention, diagnosis, and ongoing care.

From a prevention perspective, physicians have been found to place a high level of worth on primary prevention, including behavioral counseling (Mirand et al., 2002). However, they report a lack of behavioral health training, low self-efficacy, and patient resistance to change as hindering their ability to work from a prevention perspective. These barriers are mentioned not only in the context of FASD-related issues, but also when exploring prevention as related to general alcohol consumption issues. For example, Alaskan physicians view alcohol abuse as difficult to assess and themselves as unprepared to deal with patients and parents in the area of alcohol abuse; therefore, they

do not always inform patients of the dangers of alcohol on the developing fetus (Alaska FAS Prevention Steering Committee, 1995).

With regard to barriers related to FASD diagnostic services, physicians acknowledge the importance of early diagnosis for improved long-term outcomes. However, they are reluctant to render a diagnosis even when they *are* confident in its accuracy. This reluctance appeared to be grounded in several factors, including insufficient FASD diagnostic training, lack of time to devote to the diagnostic process, belief that providers more qualified would and should make the diagnosis, uncertainty about whether a diagnosis would help given the lack of treatment services, and concerns over possible stigma (Elliott et al., 2006; Gahagan et al., 2006; Mengel et al., 2006).

Individuals with complex medical and behavioral disabilities rely on physicians to provide a medical home where physicians utilize comprehensive patient-centered care approaches to coordinate and manage their patients' needs for purposes of improved medical outcomes. For pediatricians working with children experiencing FASDs, a medical home is a vital service that helps ensure children's and families' needs are met through care coordination and referrals to behavioral health services. This is an area of concern for physicians as documented in one study in which over 50% of pediatricians acknowledged having no training in treatment and care management, community resources, effective communication, confidentiality protection guidelines, and behavior counseling strategies related to alcohol use (Gahagan et al., 2006).

Conclusions

Given high prevalence rates and lifetime costs of FASDs in Alaska, it is imperative that Alaskan physicians have an adequate foundation of knowledge and sense of self-efficacy related to FASD primary and secondary prevention, diagnosis, and treatment. More specifically, they need to be knowledgeable about the effects of alcohol consumption during pregnancy and breastfeeding and must develop a sense of self-efficacy and importance related to communicating such information to their patients. Physicians are in an optimal position to educate women about the utilization of FASD-related services in Alaska, including services related to FASD education, prevention, screening, referral, diagnosis, and treatment.

Overall, past research suggests that, although physicians have basic knowledge of FASDs' clinical features, deficits in their education and skills prevent them from fulfilling their responsibilities related to preventing, detecting, and diagnosing FASDs. Barriers hindering physicians' progress go beyond limited education; they also relate to physicians' own sense of competency (or lack thereof) in addressing substance abuse, concerns related to stigma attached to FASD diagnoses, and beliefs that families are reluctant to acknowledge the existence of FASDs and follow through on comprehensive approaches to healthcare (Elliott et al., 2006; Gahagan et al., 2006; Mengel et al., 2006). Research efforts over the past decade provide a glimpse into the perspectives and practices of physicians who encounter FASDs in their patient population; however, an in-depth understanding of how to promote change in FASD-related clinical practice among

physicians remains unclear. It was the purpose of this study to fill this gap in an effort to begin to prepare and empower physicians to become engaged in FASD primary and secondary prevention, diagnosis, and treatment.

Chapter 3 Research Methods

Overview of Mixed Methods Research Approach

A mixed methods research approach was utilized to gain a comprehensive understanding of physicians' viewpoints related to FASDs. Through elaboration, convergence, and corroboration of findings from quantitative and qualitative methods, this study provides a broader and more complete range of data than would the use of either quantitative or qualitative methods alone (Johnson & Onwuegbuzie, 2004). Integrating quantitative and qualitative methodologies is commensurate with recent growth in the acceptance of qualitative research in the healthcare field (O'Cathain, Murphy, & Nicholl, 2007).

The increased depth and breadth of information drawn from quantitative and qualitative data can supply a strong basis of evidence for drawing meaningful and valid conclusions that provide guidance for developing purposeful recommendations for improving FASD primary and secondary prevention practices by Alaskan physicians. Due to the inherent strengths of a mixed methods approach, this study utilized mixed methods to achieve the goals outlined in Chapter One. More specifically, an explanatory mixed methods design was utilized.

Definition of the explanatory mixed methods design. The overall purpose of an explanatory mixed methods design is to use qualitative data to explain and enhance quantitative results (Creswell, Plano Clark, Gutmann, & Hanson, 2003). As contextualization of quantitative data greatly enhances their utility, this approach was

chosen for the current study, resulting in a three-phase process: 1) Quantitative Research Phase, 2) Qualitative Research Phase, and 3) Results Application Phase (see Figure 1). In Phase One, archival data were analyzed to explore relationships between Alaskan physicians' professional background; professional experience; personal characteristics; and level of knowledge, attitude, belief, and behavior related to FASDs. In addition, analyses were conducted analyzing the role of setting and geographic location of respondents' practices and degree to which they perceived access to resources for their patients. Phase Two entailed a qualitative approach that was inductive, confirmatory, and descriptive, using semi-structured key informant interviews with physicians practicing in rural and urban Alaska. Narrative data provided an avenue for exploring results gleaned through Phase One and allowed for developing more purposeful recommendations for FASD prevention, diagnosis, and intervention by physicians in Phase Three.

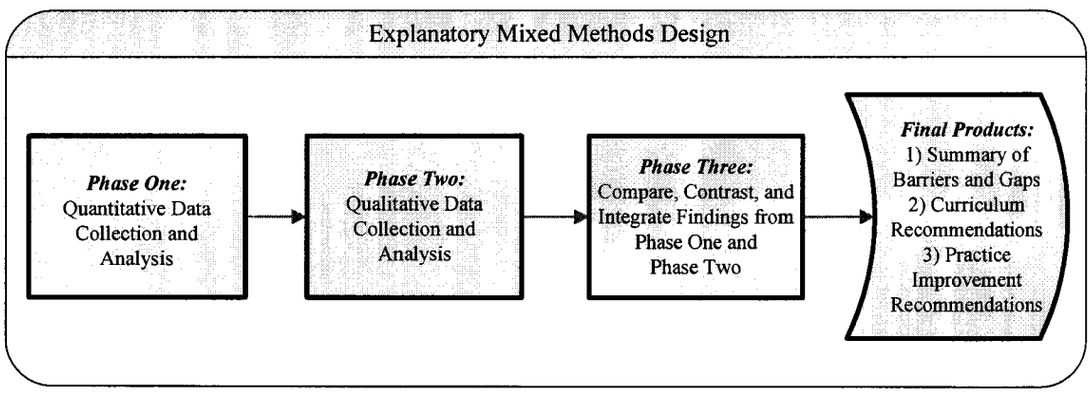


Figure 1. Study Design

Quantitative Research Methods (Phase One)

Although physicians are in a unique position to educate pregnant women and

women of child-bearing age about FASDs, little is known about the degree to which they take advantage of this opportunity. It was the purpose of this study to conduct an in-depth examination of FASD knowledge, understanding, and practices by Alaskan physicians. This study began with a quantitative phase (Phase One) that drew upon an existing quantitative database to explore knowledge, attitudes, beliefs, and behaviors of Alaskan physicians as related to FASD.

Background and procedures for use of archival data. Phase One of the study relied on archival data collected for a larger study in 2006 by the Center for Behavioral Health Research and Services (CBHRS) under contract with the Alaska State Office of FAS. Specifically, the Knowledge, Attitude, Belief, and Behavior Survey (KABB) about FASDs was administered to various health and social service providers in Alaska (CBHRS, 2007). Permission was granted by the State of Alaska and CBHRS to utilize this dataset for the purposes of the current study.

Participants

The KABB was administered to healthcare and allied healthcare or social service providers in Alaska by CBHRS in spring 2006. A total of 3,980 individuals from across the state was identified through random sampling and approached for participation in the KABB survey (CBHRS, 2007). They represented eight professional groups likely to be in contact with individuals diagnosable with FASDs. The groups included the following targeted professionals: corrections personnel, obstetricians/gynecologists, pediatricians, family physicians, public health nurses, social workers, substance abuse counselors, and

educators.

Of 3,980 mailed surveys, 3,815 reached potential respondents; the remainder turned out to have been sent to ineligible or unreachable addresses. Of the 3,815 eligible potential participants, 2,292 responded to the survey, for an overall response rate of 60.1%, ranging from 48% to 84% depending on professional target group. Public health nurses achieved the highest response rate (84%), followed by corrections personnel (65%), substance abuse counselors (64%), social workers (61%), pediatricians (60%), and educators (56%); obstetricians/gynecologists (OB/GYNs; 49%) and family physicians (48%) obtained the lowest response rate. This study utilized a subset of the archival data that was extracted to create a dataset containing only physician respondents' survey data. This subset contained KABB survey results from 243 physicians, including pediatricians (n = 61), OB/GYNs (n = 33), and family physicians (n = 149).

The subset of 243 physician respondents included 125 men and 115 women. Three respondents did not report their gender. Mean age was 49.1 years (SD = 9.5). Primary work settings as reported by the individuals were as follows: 21 (8.6%) hospital-based practice, 54 (22.2%) Native health corporation, 132 (54.3%) private practice, and 36 (14.8%) other setting. The geographic location of respondents included 116 (47.7%) individuals practicing in rural communities and 127 (53.3%) individuals practicing in urban communities, with 34% of respondents reporting that their work required them to travel to other locations in addition to their main worksite. Average patient load per week equaled an average of 64.5 individuals (SD = 32.5). The group's mean years as a

physician was 19.6 years (*SD* = 9.5) and mean years practicing medicine in Alaska was 13.9 (*SD* = 9.3). Data about physician ethnicity were not collected by the 2006 KABB survey. Tables 3 and 4 provide detailed descriptions of survey participants, separately by medical specialty and geographic practice location.

Table 3

Description of Physician Sample by Medical Specialty

Demographic Variables	*Family Practice Physicians (n = 149)*		*Obstetricians/ Gynecologists (n = 33)*		*Pediatricians (n = 61)*	
	N	*%*	*N*	*%*	*N*	*%*
Gender						
Female	67	45.0%	17	51.5%	31	50.8%
Male	79	53.0%	16	48.5%	30	49.2%
Missing	3	2.0%	0	0.0%	0	0.0%
Work Setting						
Hospital-based Practice	15	10.1%	3	9.1%	3	4.9%
Native Health Corporation	36	24.2%	3	9.1%	15	24.6%
Private Practice	68	45.6%	26	78.8%	38	62.3%
Other	30	20.1%	1	3.0%	5	8.2%
Location						
Rural	90	60.4%	11	33.3%	15	24.6%
Urban	59	39.6%	22	66.7%	46	75.4%
Itinerant Work						
No	97	65.1%	23	69.7%	41	67.2%
Yes	48	32.2%	10	30.3%	20	32.8%
Missing	4	2.7%	0	0.0%	0	0.0%
	M	*SD*	*M*	*SD*	*M*	*SD*
Age	48.4	8.9	53.3	10.6	48.8	9.8
Patient Load per Week	65.9	33.2	64.3	24.7	61.3	35.1
Years as a Physician	18.4	9.3	24.4	10.8	20.1	10.8
Years Practicing in Alaska	13.3	8.8	16.2	9.6	14.3	10.2

Table 4

Description of Physician Sample by Geographic Practice Area

Demographic Variables	*Rural (n = 116)*		*Urban (n = 127)*	
	N	*%*	*N*	*%*
Gender				
Female	50	43.1%	65	51.2%
Male	65	56.0%	60	47.2%
Missing	1	0.9%	2	1.6%
Work Setting				
Hospital-based Practice	9	7.8%	12	9.5%
Native Health Corporation	34	29.3%	20	15.8%
Private Practice	54	46.6%	78	61.4%
Other	19	16.4%	17	13.4%
Itinerant Work				
No	73	62.9%	88	69.3%
Yes	41	35.3%	37	29.1%
Missing	2	1.7%	2	1.6%
	M	*SD*	*M*	*SD*
Age	49.0	9.2	49.2	9.8
Patient Load per Week	70.7	32.3	58.9	31.8
Years as a Physician	19.3	9.9	19.9	10.2
Years Practicing in Alaska	13.7	9.0	14.2	9.6

Instrumentation

Knowledge, Attitude, Belief, and Behavior Survey (KABB). The original version of the KABB was developed and administered in 1993 by the State of Alaska Department of Health and Social Services Maternal Child and Family Health Unit. The KABB was revised in 2002 by the State of Alaska Department of Health and Social Services (DHSS) Office of Fetal Alcohol Syndrome. Questions from the original 1993

survey were used to guide the development of the 2002 KABB produced by DHSS. The KABB used in 2006 was identical to the 2002 version with the exception of two to three additional questions (depending on professional target group) added by CBHRS research staff.

The 2006 KABB version for physicians was developed to assess knowledge about FASDs, attitudes about primary and secondary FASD prevention, beliefs about alcohol consumption during pregnancy, and clinical practices pertaining to FASD-related care. Included in the survey were 34 core questions, seven demographic questions, and two open-ended questions. This study utilized 34 items that were common across all physician groups who received the KABB (see Appendix A for a copy of the KABB). These items were structured according to various response patterns, including multiple choice, yes/no forced choice responses, and Likert scale responses. Of the 34 items, 28 were based on Likert scale responses; these items were grouped into KABB subscales for this study (as described in more detail below).

Basic knowledge about FASD risk. To assess respondents' knowledge about the risk of consuming alcohol during pregnancy and breastfeeding, the KABB contains four items assessing basic knowledge about FAS risk using different choice formats depending upon question (i.e., yes and no; 0, 1 to 2, 3 to 4, or 5 or more drinks; and never during pregnancy; 1st trimester; 2nd trimester; and 3rd trimester).

Access to and Awareness of FASD resources. To gather information about respondents' access to FASD diagnostic and screening services, as well as general

FASD-related resources for patients, the KABB contains the following questions: 1) are you aware of FASD resources in your community (yes and no), and 2) do you have access to FASD screening and diagnostic services in your community (yes and no).

KABB Subscales. To increase data analysis options for the KABB, a set of subscales was developed from the 28 Likert-scale items. To maintain the intent of the original survey, all items were kept in their original content groupings and tested for scale reliability. This item organization resulted in the development of five subscales.

1. *Talk about Effects of Alcohol* (Effects): This 5-item scale assessed willingness of a respondent to talk to a pregnant friend or relative about the effect of different levels of alcohol consumption during pregnancy. Items are based on a 4-point Likert scale that ranges from 1 (*highly likely*) to 4 (*highly unlikely*). Lower scores on this subscale indicate increased willingness to talk to a pregnant friend or relative about the effects of alcohol consumption during pregnancy.
2. *Talk about Help Seeking for Alcohol Use* (Help): This 5-item scale assessed willingness of a respondent to talk to a pregnant friend or relative about getting professional help for different levels of alcohol consumption. Items are based on a 4-point Likert scale that ranges from 1 (*highly likely*) to 4 (*highly unlikely*). Lower scores on this subscale indicate increased willingness to talk to a pregnant friend or relative about getting professional help to reduce alcohol consumption during pregnancy.

3. *General FASD Knowledge* (Knowledge): This 9-item scale assessed general knowledge about prenatal alcohol exposure and its associated disorders. Items based to on a 4-point Likert scale that ranges from 1 (*strongly agree*) to 4 (*strongly disagree*). Two of the items on this subscale are reverse scored, namely, Item Three (people with FAS have mental retardation) and Item Five (people with FAS will outgrow these effects). Lower scores on this subscale indicate higher levels of knowledge related to the general risks of alcohol consumption during pregnancy.
4. *Knowledge about Cognitive Deficit* (Deficits): This 6-item scale assessed participants' knowledge related to cognitive deficits associated with prenatal alcohol exposure and FASDs. Items are based on a 4-point Likert scale that ranges from 1 (*strongly agree*) to 4 (*strongly disagree*). Lower scores on this subscale indicate higher levels of knowledge about the cognitive deficits associated with prenatal alcohol exposure.
5. *Practice Comfort and Skills* (Skills): This 5-item scale assessed physicians' perceptions related to comfort and skill levels in addressing FASD prevention and intervention in their practice. Items are based on 4-point Likert scale that ranges from 1 (*always*) to 4 (*never*). Lower scores on this subscale indicate a higher level of self-assessment of comfort and skill in addressing FASD prevention and intervention with patients.

For purpose of this study, scale reliability for the five subscales was assessed by

calculating coefficient alpha. Coefficient alpha is a statistic used to calculate scale reliability and is based on internal consistency (Cronbach, 1951). Reliability estimates for the five scales were: Effects (.74), Help (.76), Knowledge (.67), Deficits (.90), and Skills (.69). Three of the five alpha reliability estimates exceeded the acceptable level of .70 (Hatcher, 1994). The remaining two were included in this study; however, results must be interpreted cautiously in consideration of the limitations to scale reliability. Table 5 provides psychometric details and relationships between the five subscales.

Table 5

Means, Standard Deviations, Intercorrelations, and Coefficient Alpha Reliability Estimates

Variables	*M*	SD	1	2	3	4	5
1. Effects	1.55	.53	(.74)				
2. Help	1.99	.56	.69	(.76)			
3. Knowledge	1.33	.30	.20	.15	(.67)		
4. Deficits	1.29	.40	.17	.19	.60	(.90)	
5. Skills	1.93	.52	.06	.04	.28	.11	(.69)

Note: $N = 243$. Reliability estimates appear on the diagonal.

Method

Prior to implementing the 2006 KABB study, CBHRS submitted all procedures and instruments to the Institutional Review Boards of the University of Alaska Anchorage (UAA) and received full approval for the original study (see Appendix B for a copy of the approval letter). Potential respondents were informed about the survey and all procedures in a cover letter from CBHRS and the Alaska State Office of FAS. The letter requested that individuals read the informed consent document and complete the survey, if they were willing. It explained that the surveys were coded with a number that

would allow the researchers to remove individuals from a master list so that no follow-up mailings would be sent once a survey was received. These numbers were not linked to respondents in the electronic database created for survey data; thus, although the surveys were coded to reduce the need for additional mailings, respondents' identities were protected and their confidentiality guaranteed.

With regard to survey procedures, CBHRS utilized the model developed by Dillman (2000) for improving respondent return rates. A pre-letter was mailed to all professionals two weeks prior to the first mail-out of the survey describing survey purpose and procedures. The survey was then mailed with a cover letter and informed consent document. Subsequently, three follow-up reminder postcards and surveys were sent out over a period of three months beginning in March 2006. Returned surveys were edited, keyed, and rekeyed using a specially developed data entry program. CBHRS developed and utilized a SAS System 9.1.2 program to calculate statistical output.

Prior to utilizing the archival data for Phase One of this study, the research plan was submitted to the UAA Institutional Review Board (IRB) for approval. It was reviewed and approved through an expedited process. Data analyses began following this authorization.

Quantitative data analyses. SAS System 9.1.2, a comprehensive statistical software package, was used to analyze the data approved for use in this study. The study's independent variables were both continuous and categorical in nature. Continuous independent variables were age, number of years as a physician, number of

years as an Alaskan physician, and number of patient visits per week; categorical independent variables included medical specialty group (pediatricians, OB/GYNs, and family physicians), geographical practice location (rural and urban), primary work setting (hospital, Native health corporation, private practice, and other settings), and gender (female and male). The study's dependent variables included continuous and categorical variables. Continuous dependent variables included the five KABB subscales (Effects, Help, Knowledge, Deficits, and Skills), and categorical dependent variables included basic knowledge questions about FASD risk (i.e., yes and no; 0, 1 to 2, 3 to 4, or 5 or more drinks; and never during pregnancy; 1st trimester; 2nd trimester; and 3rd trimester), awareness of FASD community resources (yes and no), and access to FASD screening and diagnostic services (yes and no).

To analyze the relationships between various types of independent and dependent variables, data analyses included the use of several different statistical tests that corresponded to each of the study's questions of interest. The data analysis procedures that were utilized are outlined in Table 6.

Table 6

Quantitative Data Analysis Procedures

Research Question #1- What are physicians' levels of knowledge about FASD risk and how it is related to their personal, professional, and practice-related characteristics?		
Dependent Variables	Independent Variables	Statistical Analyses
1. Alcohol Risk Questions	1. Gender 2. Medical Specialty Area 3. Geographic Practice Location 4. Primary Practice Setting	Chi-Square Tests
Research Question #2- What are the relationships between physician's level of knowledge, attitudes, beliefs, and behaviors related to FASD and their personal-, professional-, practice-related characteristics?		
Dependent Variables	Independent Variables	Statistical Analyses
1. KABB Subscales: a. Effects b. Help c. Knowledge d. Deficits e. Skills	1. Gender 2. Medical Specialty Area 3. Geographic Practice Location 4. Primary Practice Setting	One-way MANOVAs
2. KABB Subscales: a. Effects b. Help c. Knowledge d. Deficits e. Skills	1. Age 2. Years of Experience 3. Experience in Alaska 4. Weekly Patient Load	Multiple Multivariate Regression
Research Question #3- What are the relationships between physicians' perception of access to FASD-related resources and their.		
Dependent Variables	Independent Variable	Statistical Analyses
1. Resource Awareness 2. Service Access	1. Gender 2. Medical Specialty Area 3. Geographic Practice Location 4. Primary Practice Setting	Chi-Square Tests Logistic Regression
1. Resource Awareness 2. Service Access	1. Age 2. Years of Experience 3. Experience in Alaska 4. Weekly Patient Load	Multiple Regression

Qualitative Research Methods (Phase Two)

Phase Two was implemented to contextualize quantitative findings and to better understand physician-perceived barriers and challenges to FASD primary and secondary prevention, as well as physician-desired ways of enhancing education and self-efficacy about FASD primary and secondary prevention, diagnosis, and treatment. Qualitative

methods are used in healthcare research to lessen the gap between scientific evidence and clinical practice, as well as to identify challenges in the implementation of evidence-based medicine and the practice of behavioral counseling by physicians (Green & Britten, 1998; Mirand et al., 2002). Qualitative interviews were conducted with rural and urban medical providers, stratified by medical specialties and level of FASD expertise. The participant selection plan optimized the exploration of various perspectives across geographic location, medical specialty area, and level of expertise to ensure the representation of Alaska's diversity.

Participants

Interviews were conducted with 24 physicians, including 14 women and 10 men, with a mean age of 49 years (*SD* = 10.1; ranging from 34 to 71). All physicians self-identified as Caucasian and were medical doctors licensed by the State of Alaska. Medical specialties represented were pediatrics (*n* = 8), family practice (*n* = 9), obstetrics and gynecology (*n* = 4), and family practice with subspecialty in obstetrics (*n* = 3). Physicians reported an average of 34.9 years of post-residency professional experience (*SD* = 34.9; ranging from five to 45 years) with an average of 30.2 years of practice in Alaska (*SD* = 30.2; ranging from three to 39 years). Of the participants, 13 were recognized as experts in FASD due to having specialized training in the field or serving as a physician on an FASD diagnostic team. The Alaska FASD Diagnostic Team Network consists of nine multidisciplinary teams located across the state that utilize the University of Washington Four-Digit Code for diagnostic purposes. Primary residence

was in rural communities for 11 individuals and urban communities for 13. Over 80% (n = 20) of the physicians reported having practiced medicine in both rural and urban Alaska.

Instrumentation

A key informant interview protocol was developed through the review of Phase One quantitative findings, past research on physicians' FASD-related practice, and current gaps in knowledge related to FASD primary and secondary prevention in medical settings. Consistent with the exploratory nature of Phase Two, the protocol for the key informant interviews was semi-structured and contained 11 open-ended questions. Using a semi-structured protocol facilitated exploration of unanticipated issues and pursuit of rich examples while maintaining a core set of questions to allow for comparison across physician specialty and geographic locations (Denzin & Lincoln, 1993). Special attention was given to gaining specific and in-depth information about physician-perceived barriers to FASD primary and secondary prevention, as well as physician-desired ways of enhancing education and self-efficacy about FASD primary and secondary prevention, diagnosis, and treatment. The interview took approximately one hour to complete. A copy of the key informant protocol is provided in Appendix D.

Procedures

Prior to implementation, the project was reviewed and approved by the UAA IRB. Appendix H contains a copy of the letter of approval.

Participant selection. Physicians were selected from existing healthcare

networks within Alaska by utilizing a snowball sampling technique and random selection. These two distinct processes were used to facilitate exploration of various perspectives across geographic location, medical specialty area, and level of expertise to gather data that were representative of Alaska's diversity

Snowball sampling is recognized as especially useful in contacting difficult-to-reach populations, such as medical providers practicing in rural Alaska (Berg, 2004). For purposes of this study, snowball sampling began by recruiting two statewide consultants on FASD prevention and care in medical settings. These two consultants participated in the pilot-testing of the interview protocol to provide feedback for improving the questions prior to implementation. Once pilot-testing was completed, the consultants provided an initial list of possible target participants (rural and urban; obstetricians/gynecologists, pediatricians, and family practice physicians; and FASD experts and non-experts).

To supplement the snowball selection process, physicians in each geographic area and across specialty groups were randomly selected from the Alaska State Medical Association Directory. Utilizing this additional selection process provided an opportunity to add participants to the pool of recruits with the goal of filling gaps in geographic and medical specialty representation. Eighteen of the 24 participants were selected through this process.

Participant recruitment. Potential participants were contacted via telephone and email. They were asked to participate in a 40- to 60-minute interview about FASD-related medical practices. Interviews were conducted in person or by telephone,

depending on the individual's place of residence. All interviews used the same procedures and were digitally recorded for transcription. Of 74 physicians contacted, 24 (32.4%) agreed to participate. Five physicians declined the interview at the time of first contact, and the remaining 45 physicians did not respond to any of the contact attempts. The average number of email contacts per physician was 2.6; the average number of telephone contacts was 1.75.

Interview implementation. Once interviewees agreed to participate in the study, they were asked to read and sign an informed consent document and were given an opportunity to ask questions related to the study purpose and procedures. If the interview took place via telephone, the informed consent form was faxed to the participant prior to the time of the interview and a signed consent form was returned to the researcher via fax or mail. Once on the telephone, and prior to starting the interview, the researcher reviewed the consent form with each participant to confirm her or his understanding and signature. After consent had been reconfirmed, the participant received a copy of the signed informed consent form. If the interview was held telephonically, the researcher mailed the participant a copy of the signed consent form, containing signatures of both the participant and the researcher. The 24 completed interviews were implemented in a one-on-one format by the researcher either in person ($n = 6$) or over the telephone ($n = 18$) and required an average of 48 minutes per interview. The researcher began each formal interview by reminding participants about the audiotaping of the interview, followed by asking the questions outlined in the semi-structured interview. When the

interview was complete, participants were thanked and given a $50 gift certificate. If the interview took place by telephone, the researcher mailed the $50 gift certificate with the signed consent form. All interviewees were asked if they wanted to receive aggregated research results upon the study's completion. Fourteen of the 24 physicians requested the study results.

Qualitative Data Analyses

Digital audio recordings were transcribed in MS Word and imported into NVivo software (QSR International, 2008) for qualitative data coding based on grounded theory (Stake, 1995; Strauss & Corbin, 1998). Qualitative analytic procedures followed guidelines for assessing themes, domains, issues, and items as described below (Strauss & Corbin, 1998). Emphasis was placed on analyzing for themes and constructs to increase understanding of physicians' perspectives of FASD, especially as related to prevention, diagnosis, and treatment.

Line-by-line open coding by two coders (including this researcher) of six transcripts was used to create a list of potential free nodes (concepts). Each free node was discussed by the two coders and examined for retention or deletion. Retained free nodes were then explicitly defined. During this initial stage, coders met regularly to review newly emerging free nodes and confirm that all phenomena were accounted for during the open coding process. Disagreements in coding were addressed by merging coded interviews prior to the coding meetings, identifying disagreements in the coding by comparing user coding stripes, and reviewing whether a code was applied appropriately

(subsequently coding it to both projects) or applied inappropriately (subsequently un-coding it from both projects). New free nodes were created only if it was not possible to incorporate a theme into an existing free node definition. The coding process was iterative in nature (i.e., any changes to the codebook or process were applied to previously coded interviews). Upon completion of the open coding stage, a codebook containing detailed definitions of each node was developed to assist coders in maintaining reliability.

Following this process, the first six interviews were recoded by both coders to establish interrater reliability. Based on these initial six interviews, it was established that coders were coding in an almost identical manner with more than 90% agreement across interviews and paragraphs. The remaining 18 interviews were double-coded and compared in intervals of six transcripts to ensure maintenance of interrater reliability above 90% agreement. Review of the 24 double-coded interviews revealed an overall interrater reliability rate of 97.1%, confirming a high level of accuracy and low level of drift.

Chapter 4 Quantitative Research Findings

Analysis of Physicians' Knowledge about FASD Risk

Overall physician FASD risk knowledge. As a component of the KABB survey, physicians responded to a set of four basic knowledge questions related to the risk of alcohol consumption during pregnancy and breastfeeding. These four items assessed basic knowledge about FAS risk using different choice formats depending upon question (i.e., yes and no; 0, 1 to 2, 3 to 4, or 5 or more drinks; and never during pregnancy; 1st trimester; 2nd trimester; and 3rd trimester).Over 85% of physicians expressed the opinion that it was not appropriate for a woman to consume alcohol during pregnancy, with approximately 15% of respondents considering an occasional alcoholic beverage to be acceptable. Similarly, over 76% of physicians noted that no amount of alcohol during pregnancy was safe. The remaining 24% of respondents identified what they considered to be a safe number of alcoholic drinks for consumption during pregnancy, with approximately 12% identifying one or two drinks, 7% identifying three to four drinks, and 4% identifying five or more drinks. With regard to pregnancy trimester during which alcohol consumption would be safest, over 79% responded that drinking during any trimester of pregnancy was unsafe. The remaining 21% identified a specific trimester when drinking would probably be safe, with most naming the third trimester. As for perceptions about postnatal alcohol exposure, 61% of physicians reported that it was acceptable for women to have an occasional alcoholic beverage while breastfeeding. Table 7 provides specific findings related to physicians' responses to this

set of questions.

Table 7

Basic Knowledge about FASD Risk Items

	N	%
1) It is okay for pregnant women to have an occasional alcoholic beverage:		
Yes	33	14.1%
No	201	85.9%
2) It is okay for nursing women to have an occasional alcoholic beverage		
Yes	140	61.4%
No	88	38.6%
3) Safe amount of alcohol a women could drink during pregnancy:		
0 drinks	162	76.4%
1 or 2 drinks	27	12.7%
3 or 4 drinks	15	7.1%
5 or more drinks	8	3.8%
4) Trimester that drinking would probably be safe:		
Never	176	79.6%
1st trimester	4	1.8%
2nd trimester	11	5.0%
3rd trimester	30	13.6%

FASD risk knowledge and physician characteristics. To explore relationships between physician characteristics and FASD knowledge, participants were categorized based on gender (female and male), medical specialty group (pediatricians, OB/GYNs, and family physicians), geographical practice location (rural and urban), and primary work setting (hospital, Native health corporation, private practice, and other). All categorizations were based on self-identified characteristics, with the exception of geographical practice location. This categorization was based on the population size of the physician's self-reported practice community. Urban was defined as communities with discrete or contiguous populations of over 35,000. All other communities were considered rural.

Physician FASD risk knowledge by gender. To determine the relationship between FASD risk knowledge and physician gender, chi-square tests of independence were conducted for each of the four FASD risk questions. Table 8 provides an overview of the frequency with which physicians correctly responded to the risk questions broken down by gender. The 2 x 2 comparisons were made based on item responses (correct/incorrect) and physician gender (female/male). The chi-square analyses revealed no significant differences on any of the four items.

Table 8

Basic Knowledge about FASD Risk Items by Gender

	Male (n = 124)		*Female (n = 107)*		*Sig. Level**
	N	*%*	*N*	*%*	
Percent responding correctly to the following questions about FAS risks:					
1) Is it okay for a pregnant woman to have an occasional alcoholic beverage? (percentage answering no)	104	83.9%	94	87.9%	.45
2) Is it okay for a nursing mother to have an occasional alcoholic beverage? (percentage answering no)	45	38.1%	41	38.3%	.98
3) What do you think is the most alcohol that a woman could drink during her pregnancy that would probably be safe for her developing baby? (percentage answering 0 drinks)	86	78.9%	74	74.0%	.41
4) When do you think that a woman could drink during her pregnancy that would probably be safe for her developing baby? (percentage answering never)	93	80.9%	81	77.9%	.62

*Significance determined by chi-square analysis.

Physician FASD risk knowledge by medical specialty. To determine the relationship between FASD risk knowledge and physician medical specialty, chi-square tests of independence were conducted for each of the four FASD risk questions. Table 9 provides an overview of the frequency with which physicians correctly responded to the risk questions broken down by medical specialty. The 2 x 3 comparisons were made

based on item responses (correct/incorrect) and medical specialty groups (pediatricians, OB/GYNs, and family physicians). The chi-square analyses revealed a significant difference on one of the four items, namely Item 3, *What is a safe amount of alcohol a woman could drink during pregnancy?* The relationship between respondents' beliefs about a safe amount of alcohol consumption and medical specialty was significant, $X^2(2, N = 212) = 6.32, p = .04$. Pediatricians were more likely to identify zero drinks during pregnancy as the safest amount than were family practice physicians and OB/GYNs.

Table 9

Basic Knowledge about FASD Risk Items by Medical Specialty

	Family Practice (n = 149)		*Obstetricians/ Gynecologists (n = 33)*		*Pediatricians (n = 61)*		*Sig. Level**
	N	*%*	*N*	*%*	*N*	*%*	
Percent responding correctly to the following questions about FAS risks:							
1) Is it okay for a pregnant woman to have an occasional alcoholic beverage? (percentage answering no)	127	88.2%	24	75.0%	50	86.2%	.15
2) Is it okay for a nursing mother to have an occasional alcoholic beverage? (percentage answering no)	63	44.7%	9	29.0%	16	28.6%	.06
3) What do you think is the most alcohol that a woman could drink during her pregnancy that would probably be safe for her developing baby? (percentage answering 0 drinks)	99	75.6%	18	62.1%	45	86.5%	.04
4) When do you think that a woman could drink during her pregnancy that would probably be safe for her developing baby? (percentage answering never)	108	78.2%	24	77.4%	44	84.6%	.59

*Significance determined by chi-square analysis.

Physician FASD risk knowledge by geographic practice location. To determine the relationship between FASD risk knowledge and geographic practice location, chi-square tests of independence were conducted for each of the four FASD risk questions. Table 10 provides an overview of the frequency with which physicians correctly

responded to the risk questions broken down by geographic practice location. The 2 x 2 comparisons were made based on item responses (correct/incorrect) and geographic practice location (rural and urban). The chi-square analyses revealed significant differences on three (Items 1, 3, and 4) of the four items.

Table 10.

Basic Knowledge about FASD Risk Items by Geographic Practice Location

	Rural (n = 116)		*Urban (n = 127)*		*Sig. Level**
	N	*%*	*N*	*%*	
Percent responding correctly to the following questions about FAS risks:					
1) Is it okay for a pregnant woman to have an occasional alcoholic beverage? (percentage answering no)	103	92.8%	98	79.7%	.00
2) Is it okay for a nursing mother to have an occasional alcoholic beverage? (percentage answering no)	45	41.7%	43	35.8%	.37
3) What do you think is the most alcohol that a woman could drink during her pregnancy that would probably be safe for her developing baby? (percentage answering 0 drinks)	85	83.3%	77	70.0%	.02
4) When do you think that a woman could drink during her pregnancy that would probably be safe for her developing baby? (percentage answering never)	91	85.1%	85	74.6%	.05

*Significance determined by chi-square analysis.

First, the relationship between respondents' beliefs about whether alcohol consumption is acceptable during pregnancy (Item 1) and geographic practice location was significant, $X^2(1, N = 234) = 8.29, p = .00$. Rural physicians were more likely to report that alcohol consumption is not appropriate during pregnancy than were urban physicians. Second, the relationship between respondents' beliefs about a safe amount of alcohol consumption (Item 3) and geographic practice area was significant, $X^2(1, N = 212) = 5.22, p = .02$. Rural physicians were more likely to identify zero drinks during pregnancy as the safest amount than were urban physicians. Third, the relationship

between respondents' beliefs about when it would be safe to consume alcohol during pregnancy (Item 4) and geographic practice location was significant, $X^2(1, N = 221) = 3.74, p = .05$. Rural physicians were more likely to report that no trimester during pregnancy was safe for alcohol consumption than were urban physicians.

Physician FASD risk knowledge by primary work setting. To determine the relationship between FASD risk knowledge and primary work setting, chi-square tests of independence were conducted for each of the four FASD risk questions. Table 11 provides an overview of the frequency with which physicians correctly responded to the risk questions broken down by primary work setting. The 2 x 4 comparisons were made based on item responses (correct/incorrect) and work setting (hospital-based practice, Native health corporation, private practice, and other setting). The chi-square analyses revealed no significant differences on any of the four items.

Table 11

Basic Knowledge about FASD Risk Items by Primary Work Setting

	Hospital-based Practice (n = 21)		*Native Health Corporation (n = 51)*		*Private Practice (n = 128)*		*Other Setting (n = 34)*		*Sig Level**
	N	*%*	*N*	*%*	*N*	*%*	*N*	*%*	
Percent responding correctly to the following questions about FAS risks:									
1) Is it okay for a pregnant woman to have an occasional alcoholic beverage? (percentage answering no)	16	76.2%	46	90.2%	109	85.2%	30	88.2%	.47
2) Is it okay for a nursing mother to have an occasional alcoholic beverage? (percentage answering no)	7	33.3%	19	35.9%	49	39.8%	13	41.9%	.89
3) What do you think is the most alcohol that a woman could drink during her pregnancy that would probably be safe for her developing baby? (percentage answering 0 drinks)	15	75.0%	40	81.6%	82	71.3%	25	89.3%	.17
4) When do you think that a woman could drink during her pregnancy that would probably be safe for her developing baby? (percentage answering never)	14	73.7%	41	80.4%	94	79.7%	27	81.8%	.90

*Significance determined by chi-square analysis.

Analysis of Physician Characteristics and KABB Subscales

Effects of gender, medical specialty, practice location, and work setting. A series of one-way multivariate analyses of variance (MANOVA) were conducted to assess the relationship of four separate independent variables: gender (male and female); medical specialty (pediatricians, OB/GYNs, and family physicians); practice location (rural and urban); and work setting (hospital, Native health corporation, private practice, and other setting). Dependent variables for these MANOVAs were the five KABB subscales (Effects, Help, Knowledge, Deficits, and Skills). Only main effects were explored; the use of a factorial design was not possible given sample size limitations.

Results of the four one-way MANOVAs revealed statistical significance only for medical specialty, $F(10, 458) = 1.88, p < .05$. Univariate analyses of medical specialty revealed significant differences for one of the five dependent variables, namely, Skills. A follow-up post hoc test revealed pediatricians ($M = 1.76$, $SD = .52$) rated their level of comfort and skill with FASD primary and secondary prevention as higher than did OB/GYNs ($M = 2.12$, $SD = .53$), but not family physicians ($M = 2.0$, $SD = .50$). The other three MANOVAs failed to reach statistical significance: gender, $F(5, 228) = 1.81$, *ns.*, practice location $F(5, 230) = 0.63$, *ns.*, and work setting, $F(15, 630) = 0.08$, *ns.* Descriptive statistics are shown in Tables 12 through 16 and Figures 2 through 6, including means and standard deviations for all subscales and their individual items.

Table 12

Effects by Gender, Medical Specialty, Practice Location and Primary Work Setting

		Gender		*Medical Specialty*			*Practice Location*		*Primary Work Setting*				
Effects		*Male (n = 124)*	*Female (n = 107)*	*Family Practice (n = 149)*	*OB/GYNs (n = 33)*	*Peds (n = 61)*	*Rural (n = 116)*	*Urban (n = 127)*	*Hospital-based Practice (n = 21)*	*Native Health Corp (n = 51)*	*Private Practice (n = 128)*	*Other Setting (n = 34)*	*All (n = 243)*
Total Scale Score	*M*	1.6	1.6	1.5	1.5	1.6	1.5	1.6	1.6	1.5	1.6	1.5	1.6
	SD	0.5	0.5	0.5	0.5	0.5	0.5	0.5	0.6	0.5	0.5	0.5	0.5
Indicate how likely it is that you would talk to a pregnant friend or relative about the effects of alcohol on the developing baby if:													
Your friend or relative drank 1 or 2 alcoholic beverages during her **entire** pregnancy	*M*	2.5	2.6	2.5	2.5	2.8	2.4	2.7	2.8	2.5	2.6	2.3	2.6
	SD	1.1	1.2	1.2	1.2	1.2	1.2	1.2	1.3	1.1	1.2	1.2	1.2
Your friend or relative drank 1 or 2 alcoholic beverages **a month** during her pregnancy	*M*	1.8	1.7	1.8	1.6	1.9	1.7	1.8	1.9	1.8	1.8	1.6	1.8
	SD	1.0	0.9	0.9	1.0	1.0	0.9	1.0	1.1	1.0	1.0	0.8	0.9
Your friend or relative drank 1 or 2 alcoholic beverages **a week** during her pregnancy	*M*	1.3	1.3	1.3	1 2	1.4	1.3	1.4	1.5	1.3	1.3	1.3	1.3
	SD	0.7	0.6	0.6	0.6	0.8	0.5	0.8	0.8	0.6	0.7	0.7	0.7
Your friend or relative drank **5 or more** alcoholic beverages on any one occasion during her pregnancy	*M*	1.1	1.1	1.1	1.1	1.1	1.1	1.1	1	1.1	1.1	1.1	1.1
	SD	0.3	0.3	0.3	0.2	0.2	0.3	0.3	0.2	0.2	0.2	0.4	0.3
Your friend or relative drank 1 or 2 alcoholic beverages **a day** during her pregnancy	*M*	1.1	1.1	1.1	1.1	1.1	1.1	1.1	1	1.1	1.1	1.1	1.1
	SD	0.3	0.3	0.3	0.3	0.2	0.4	0.2	0	0.3	0.3	0.4	0.3

Scale ranges from 1 (*highly likely*) to 4 (*highly unlikely*)

Table 13

Help by Gender, Medical Specialty, Practice Location and Primary Work Setting

		Gender		*Medical Specialty*			*Practice Location*		*Primary Work Setting*				
Help		*Male (n = 124)*	*Female (n = 107)*	*Family Practice (n = 149)*	*OB/GYNs (n = 33)*	*Peds (n = 61)*	*Rural (n = 116)*	*Urban (n = 127)*	*Hospital-based Practice (n = 21)*	*Native Health Corp (n = 51)*	*Private Practice (n = 128)*	*Other Setting (n = 34)*	*All (n = 243)*
Total Scale Score	*M*	2.0	1.9	2.0	1.9	2.1	2.0	2.0	2.0	2.0	2.0	2.0	2.0
	SD	0.6	0.5	0.6	0.6	0.5	0.5	0.6	0.6	0.5	0.6	0.6	0.6
Indicate how likely it is that you would talk to a pregnant friend or relative about seeking professional services to help her stop drinking if:													
Your friend or relative drank 1 or 2 alcoholic beverages during her **entire** pregnancy	*M*	3.2	3.3	3.2	3.1	3.4	3.2	3.3	3.3	3.4	3.2	3.1	3.2
	SD	0.9	0.9	0.9	1.0	0.8	0.9	1.0	1.1	0.8	1.0	0.9	0.9
Your friend or relative drank 1 or 2 alcoholic beverages **a month** during her pregnancy	*M*	2.6	2.5	2.5	2.5	2.7	2.5	2.6	2.7	2.6	2.5	2.6	2.6
	SD	1.0	1.0	1.0	1.1	1.0	1.0	1.0	1.2	1.0	1.0	0.9	1.0
Your friend or relative drank 1 or 2 alcoholic beverages **a week** during her pregnancy	*M*	1.9	1.7	1.8	1.6	1.9	1.8	1.8	1.9	1.8	1.8	2.0	1.8
	SD	0.9	0.9	0.8	0.9	1.0	0.8	0.9	0.9	0.7	0.9	0.9	0.9
Your friend or relative drank **5 or more** alcoholic beverages on any one occasion during her pregnancy	*M*	1.2	1.1	1.2	1.1	1.1	1.1	1.2	1.1	1.1	1.1	1.3	1.1
	SD	0.5	0.3	0.5	0.2	0.4	0.4	0.5	0.4	0.3	0.4	0.6	0.4
Your friend or relative drank 1 or 2 alcoholic beverages **a day** during her pregnancy	*M*	1.2	1.2	1.2	1.2	1.2	1.2	1.2	1.2	1.2	1.3	1.1	1.2
	SD	0.6	0.5	0.5	0.6	0.4	0.6	0.5	0.5	0.5	0.6	0.4	0.5

Scale ranges from 1 (*highly likely*) to 4 (*highly unlikely*)

Table 14

Knowledge by Gender, Medical Specialty, Practice Location, and Primary Work Setting

		Gender		*Medical Specialty*			*Practice Location*		*Primary Work Setting*				
Knowledge		*Male (n = 124)*	*Female (n = 107)*	*Family Practice (n = 149)*	*OB/GYNs (n = 33)*	*Peds (n = 61)*	*Rural (n = 116)*	*Urban (n = 127)*	*Hospital-based Practice (n = 21)*	*Native Health Corp (n = 51)*	*Private Practice (n = 128)*	*Other Setting (n = 34)*	*All (n = 243)*
Total Scale Score	*M*	1.3	1.3	1.3	1.3	1.3	1.3	1.3	1.3	1.3	1.3	1.4	1.3
	SD	0.3	0.3	0.3	0.4	0.3	0.3	0.3	0.2	0.3	0.3	0.3	0.3
People with FAS have a set of birth defects	*M*	1.5	1.6	1.6	1.5	1.4	1.6	1.5	1.5	1.5	1.6	1.4	1.5
	SD	0.7	0.8	0.8	0.8	0.6	0.8	0.7	0.6	0.8	0.8	0.7	0.8
People with FAS have brain damage	*M*	1.3	1.4	1.4	1.3	1.3	1.4	1.3	1.5	1.2	1.4	1.4	1.3
	SD	0.6	0.6	0.6	0.7	0.5	0.6	0.6	0.6	0.5	0.6	0.6	0.6
People with FAS have mental retardation*	*M*	1.7	1.8	1.8	1.6	1.7	1.8	1.7	1.6	1.6	1.7	1.9	1.7
	SD	0.7	0.8	0.7	0.8	0.8	0.8	0.7	0.6	0.7	0.8	0.8	0.7
People with FAS are affected physically	*M*	1.4	1.6	1.5	1.5	1.4	1.5	1.4	1.4	1.4	1.5	1.6	1.5
	SD	0.6	0.6	0.6	0.8	0.6	0.7	0.6	0.6	0.5	0.7	0.7	0.6
People with FAS will outgrow these effects*	*M*	1.1	1.1	1.0	1.1	1.0	1.1	1.1	1.0	1.1	1.1	1.3	1.1
	SD	0.4	0.3	0.4	0.5	0.1	0.4	0.4	0.0	0.2	0.4	0.6	0.4
People with FAS have these effects through adulthood	*M*	1.3	1.3	1.2	1.3	1.4	1.3	1.3	1.3	1.2	1.3	1.4	1.3
	SD	0.6	0.7	0.6	0.8	0.9	0.6	0.8	0.8	0.5	0.7	0.8	0.7
Drinking alcohol during pregnancy can cause birth defects	*M*	1.1	1.1	1.1	1.1	1.1	1.1	1.1	1.1	1.1	1.1	1.1	1.1
	SD	0.4	0.3	0.3	0.4	0.2	0.4	0.3	0.3	0.2	0.4	0.3	0.3
The only cause of FAS is alcohol consumption by a birth mother during her pregnancy	*M*	1.3	1.1	1.2	1.2	1.2	1.2	1.2	1.1	1.2	1.2	1.2	1.2
	SD	0.6	0.5	0.5	0.7	0.6	0.5	0.6	0.3	0.5	0.6	0.5	0.5
FAS is preventable	*M*	1.1	1.0	1.1	1.0	1.1	1.1	1.0	1.0	1.1	1.1	1.1	1.1
	SD	0.3	0.3	0.3	0.0	0.4	0.4	0.2	0.2	0.2	0.3	0.2	0.3

Scale ranges from 1 (*strongly agree*) to 4 (*strongly disagree*). * Items were reverse scored.

Table 15

Deficits by Gender, Medical Specialty, Practice Location and Primary Work Setting

		Gender		*Medical Specialty*			*Practice Location*		*Primary Work Setting*				
Deficits		*Male (n = 124)*	*Female (n = 107)*	*Family Practice (n = 149)*	*OB/GYNs (n = 33)*	*Peds (n = 61)*	*Rural (n = 116)*	*Urban (n = 127)*	*Hospital-based Practice (n = 21)*	*Native Health Corp (n = 51)*	*Private Practice (n = 128)*	*Other Setting (n = 34)*	*All (n = 243)*
Total Scale Score	*M*	1.3	1.3	1.3	1.3	1.2	1.3	1.3	1.3	1.2	1.3	1.3	1.3
	SD	0.4	0.4	0.4	0.5	0.4	0.4	0.4	0.4	0.3	0.4	0.4	0.4
FAS affects a person's motor skills	*M*	1.5	1.5	1.6	1.3	1.4	1.6	1.4	1.3	1.6	1.4	1.5	1.5
	SD	0.6	0.6	0.6	0.6	0.6	0.6	0.6	0.5	0.8	0.6	0.6	0.6
FAS affects a person's memory	*M*	1.4	1.4	1.4	1.4	1.2	1.4	1.3	1.3	1.4	1.4	1.4	1.4
	SD	0.5	0.6	0.6	0.6	0.5	0.6	0.5	0.5	0.6	0.5	0.6	0.5
FAS affects a person's judgment	*M*	1.3	1.2	1.3	1.2	1.2	1.3	1.3	1.2	1.2	1.3	1.3	1.3
	SD	0.4	0.4	0.5	0.5	0.4	0.5	0.4	0.4	0.4	0.5	0.5	0.4
FAS affects a person's ability to plan	*M*	1.2	1.2	1.3	1.2	1.2	1.2	1.2	1.2	1.1	1.3	1.3	1.2
	SD	0.4	0.4	0.4	0.5	0.4	0.4	0.4	0.4	0.3	0.5	0.4	0.4
FAS affects a person's ability to reason	*M*	1.3	1.2	1.3	1.2	1.2	1.3	1.3	1.3	1.2	1.3	1.3	1.3
	SD	0.5	0.5	0.5	0.5	0.4	0.5	0.4	0.5	0.4	0.5	0.5	0.5
FAS affects a person's ability to learn	*M*	1.2	1.2	1.2	1.2	1.2	1.2	1.2	1.2	1.2	1.2	1.3	1.2
	SD	0.4	0.4	0.4	0.5	0.4	0.5	0.4	0.4	0.4	0.4	0.5	0.4

Scale ranges from 1 (*strongly agree*) to 4 (*strongly disagree*)

Table 16

Skills by Gender, Medical Specialty, Practice Location and Primary Work Setting

		Gender		*Medical Specialty*			*Practice Location*		*Primary Work Setting*				
Skills		*Male (n = 124)*	*Female (n = 107)*	*Family Practice (n = 149)*	*OB/GYNs (n = 33)*	*Peds (n = 61)*	*Rural Physician (n = 116)*	*Urban Physicians (n = 127)*	*Hospital-based Practice (n = 21)*	*Native Health Corp (n = 51)*	*Private Practice (n = 128)*	*Other Setting (n = 34)*	*All (n = 243)*
Total Scale Score	*M*	1.9	2.0	2.0	2.1	1.7	1.9	1.9	1.9	1.8	2.0	2.0	1.9
	SD	0.5	0.5	0.5	0.5	0.5	0.5	0.5	0.5	0.5	0.5	0.6	0.5
Feel it is important to address alcohol abuse in patients and family	*M*	1.0	1.1	1.0	1.0	1.1	1.0	1.1	1.1	1.0	1.1	1.0	1.1
	SD	0.2	0.3	0.2	0.0	0.4	0.2	0.3	0.4	0.2	0.3	0.2	0.2
Feel comfortable making a chart notation of FAS	*M*	1.5	1.5	1.6	1.4	1.4	1.5	1.5	1.4	1.4	1.5	1.7	1.5
	SD	0.8	0.7	0.8	0.8	0.7	0.8	0.7	0.6	0.7	0.8	0.8	0.7
Feel comfortable diagnosing FAS	*M*	2.2	2.6	2.5	2.8	1.9	2.4	2.3	2.3	2.2	2.4	2.7	2.4
	SD	1.0	0.9	0.9	1.0	0.9	1.0	0.9	0.9	1.0	1.0	1.0	1.0
Feel I have appropriate skills and knowledge to deal with patient who have problems with alcohol abuse	*M*	2.1	2.4	2.1	2.5	2.4	2.2	2.3	1.9	2.1	2.3	2.2	2.2
	SD	0.8	0.9	0.8	0.9	1.0	0.8	0.9	0.8	0.8	0.9	0.9	0.9
Feel I have appropriate skills and knowledge to deal with patients with FAS	*M*	2.5	2.5	2.7	2.9	1.9	2.5	2.5	2.5	2.3	2.5	2.6	2.5
	SD	0.8	0.9	0.8	1.0	0.7	0.8	0.9	0.9	0.8	0.9	0.8	0.9

Scale ranges from 1 (*strongly agree*) to 4 (*strongly disagree*)

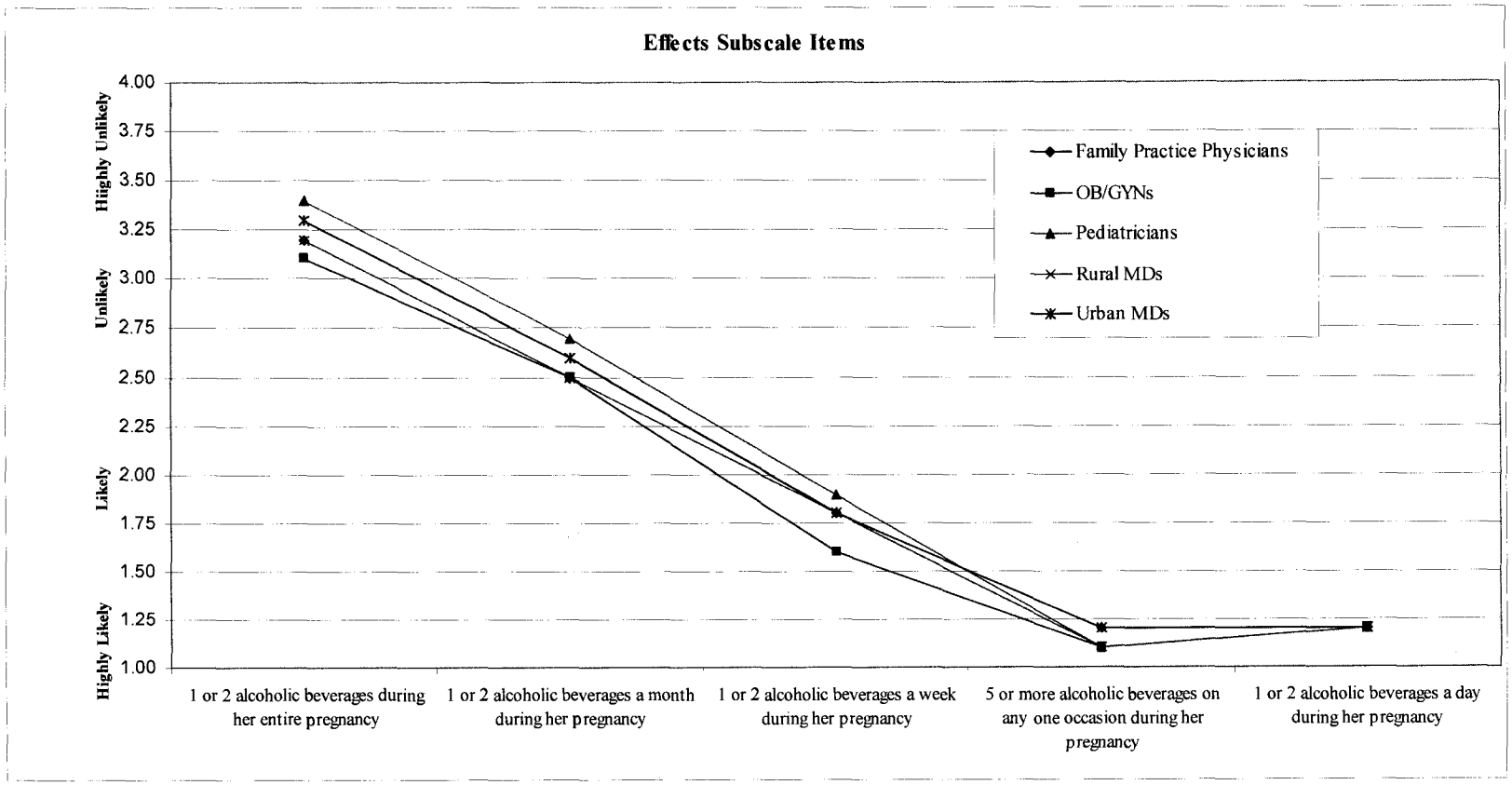


Figure 2. Effects Subscale Items by Physician Characteristics

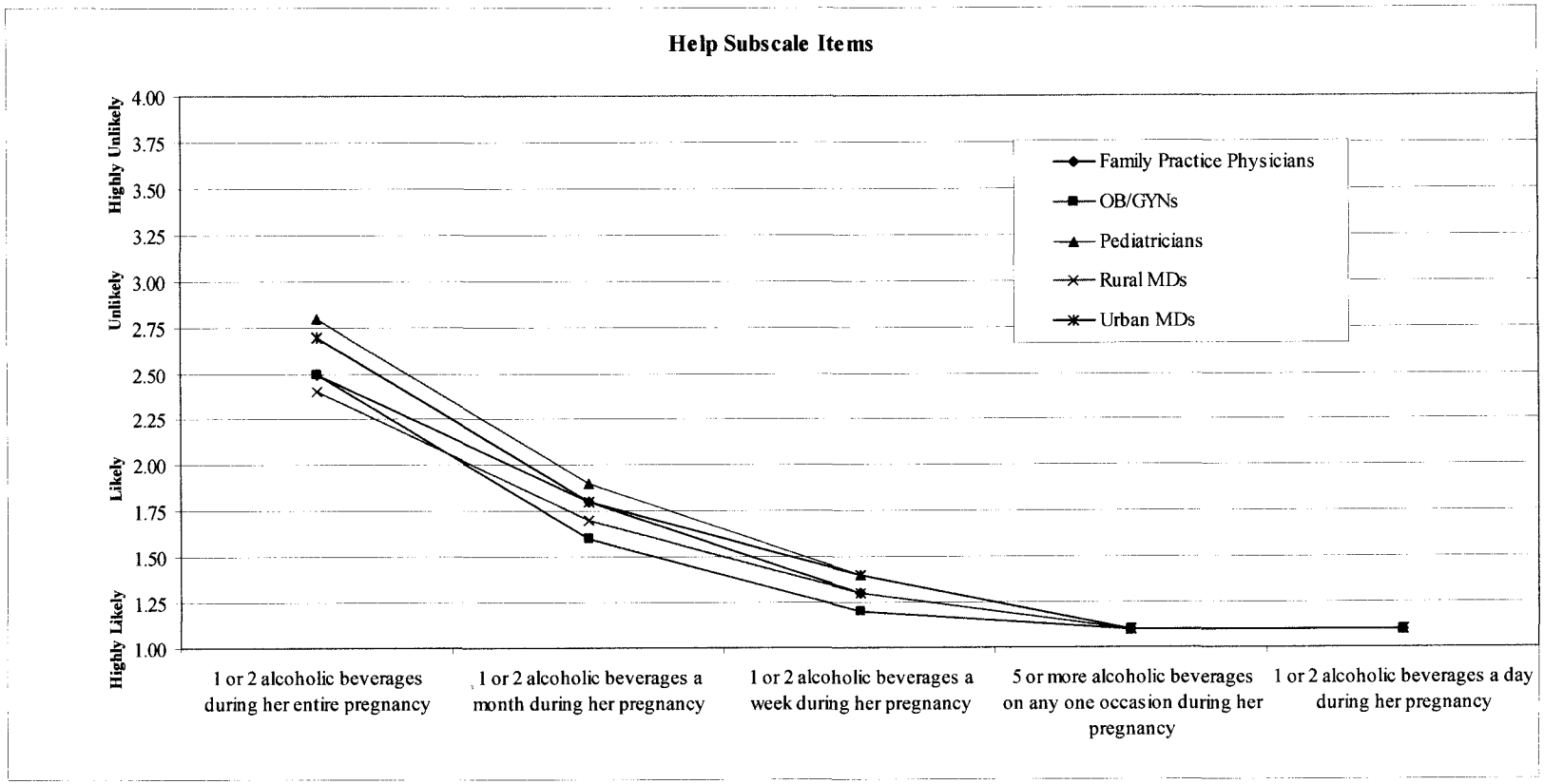
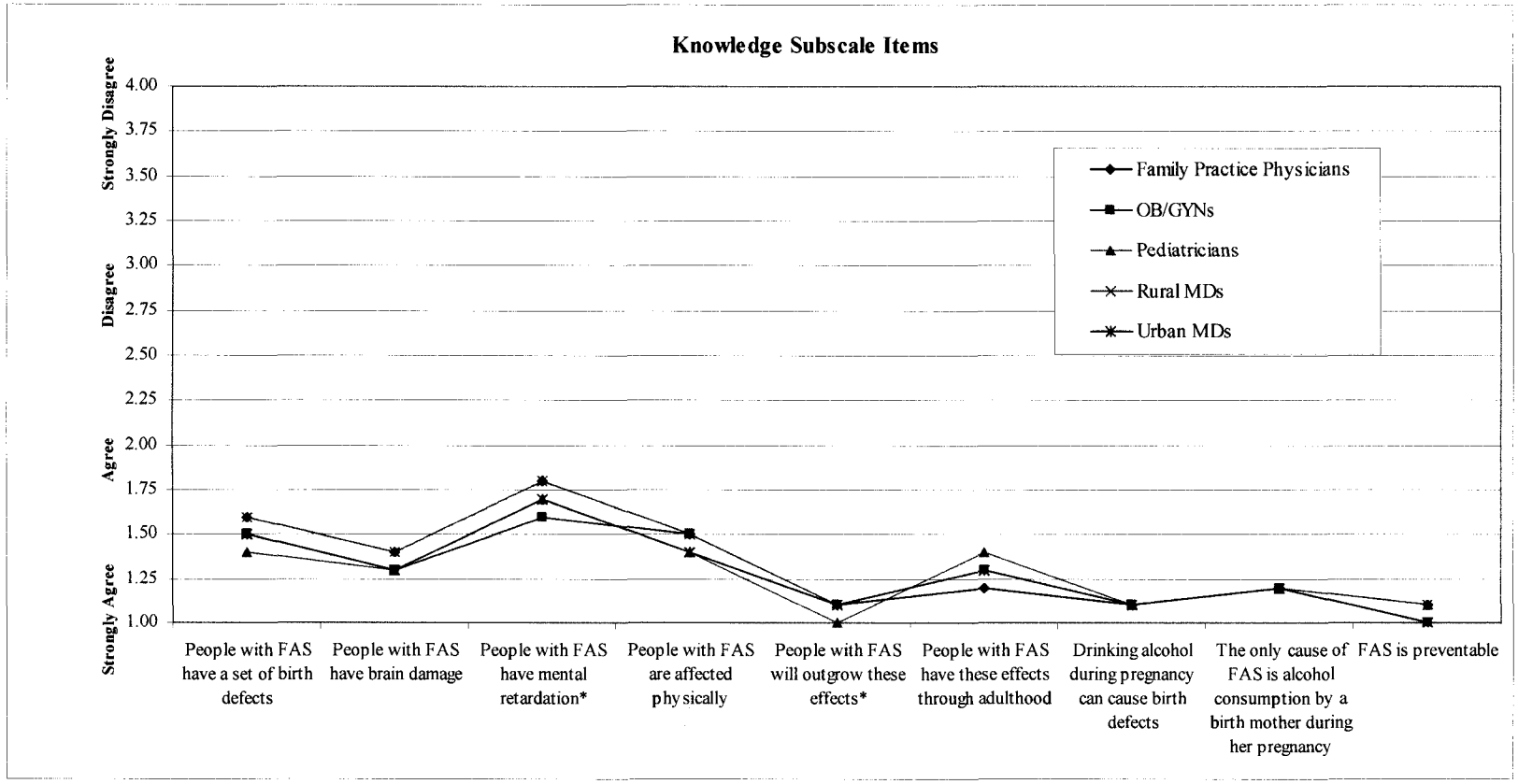


Figure 3. Help Subscale Items by Physician Characteristics



* Items were reverse scored.

Figure 4. Knowledge Subscale Items by Physician Characteristics

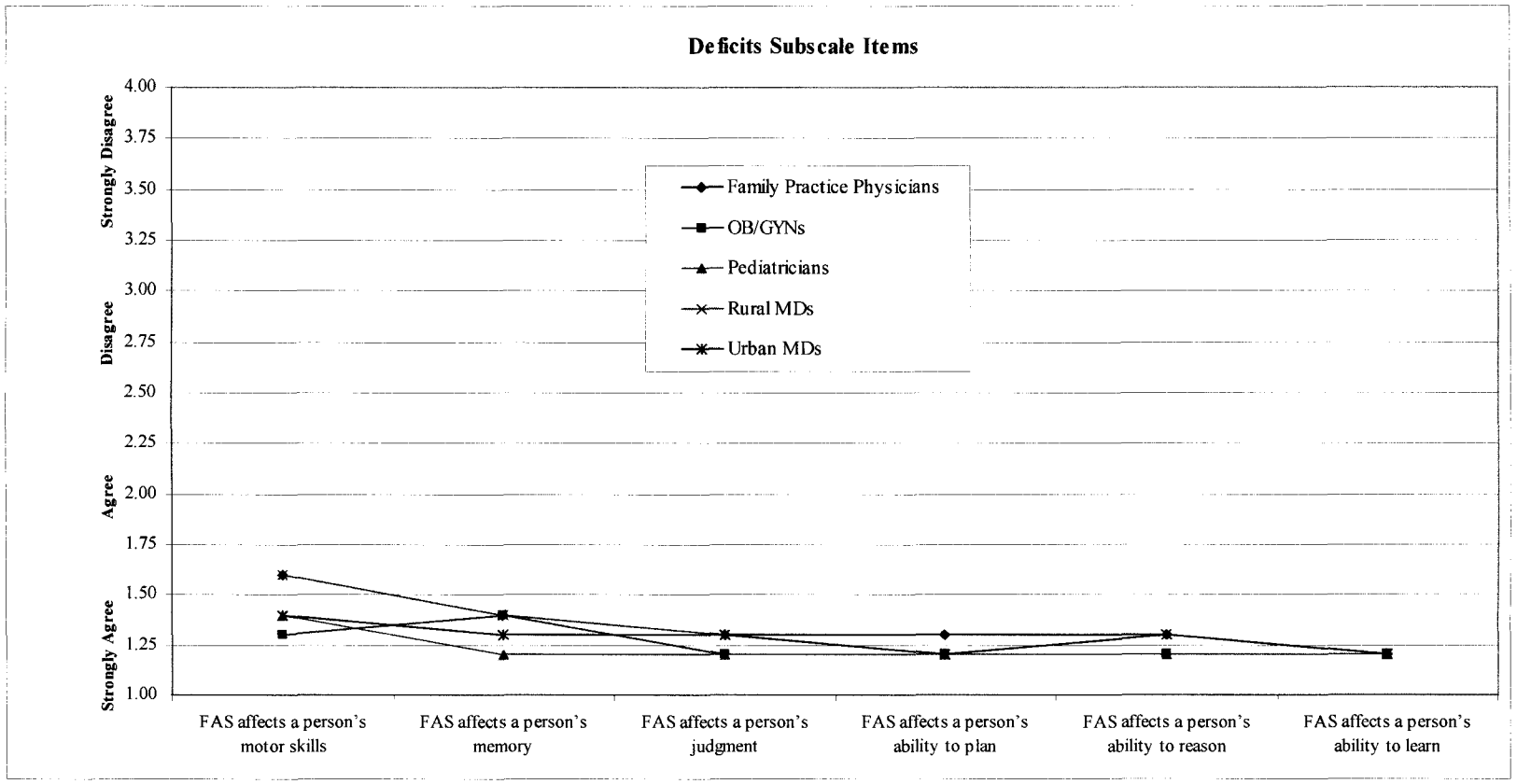


Figure 5. Deficits Subscale Items by Physician Characteristics

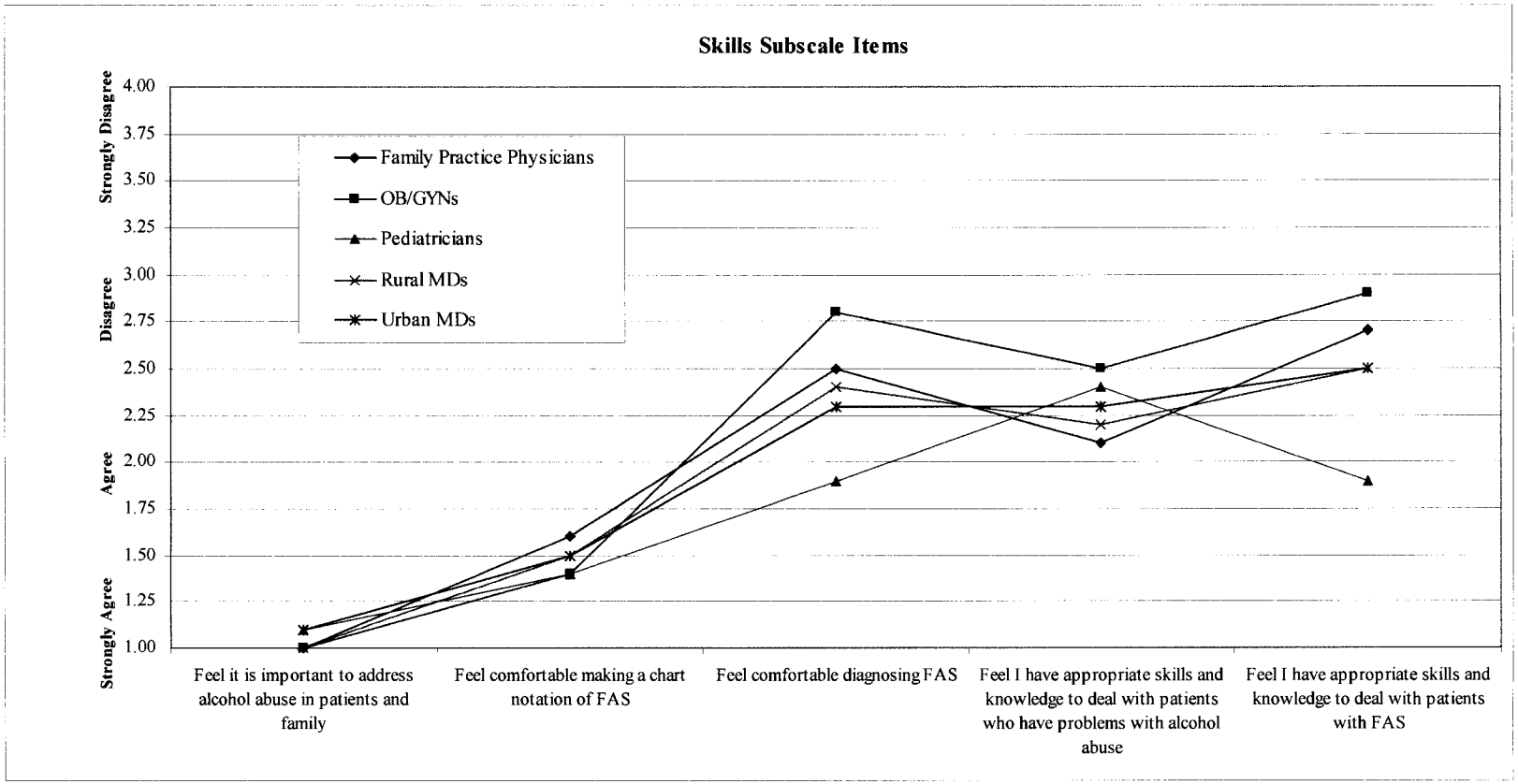


Figure 6. Skill Subscale Items by Physician Characteristics

Effects of age, years of practice, and patient load. Using multivariate regression analysis, relationships were explored between the predictor variables of age, years of physician experience, years of experience in Alaska, and number of patients served per week and the criterion variables of the KABB subscales (Effects, Help, Knowledge, Deficits, and Skills). Analyses revealed no significant multivariate effects with the for predictor variables, including age, $F(5, 202) = .38$, *ns.*, years of experience, $F(5, 202) = .08$, *ns.*, years of Alaskan experience, $F(5, 202) = .42$, *ns.*, and weekly patient load, $F(55, 202) = 1.49$, *ns.*

Analyses of Physician Awareness of and Access to FASD-related Resources

Physicians were asked whether they were aware of local FASD community resources and had access to screening and diagnostic services in their community. With regard to awareness of local FASD community resources, overall, 177 (72.8%) of physicians responded affirmatively. Results of chi-square analyses revealed statistically significant differences only for medical specialty, 86.9% ($n = 53$) of the pediatricians were aware of community resources, followed by 69.7% ($n = 23$) of the OB/GYNs and 67.8% ($n = 101$) of the family physicians, $X^2(2, N = 243) = 8.17$, $p = .02$. Although non-significant, some slight variations were present with regard to other physician characteristics. Physicians working in other settings (80.6%; $n = 29$) had the highest percentage of respondents who acknowledged awareness of resources, followed by 76.2% ($n = 16$) of physicians working in a hospital, 75.9% ($n = 41$) of physicians working in a Native health corporation, and 68.9% ($n = 91$) of physicians working in

private practice, $X^2(3, N = 234) = 3.78, p = .29$. More physicians practicing in rural communities (75.0%; $n = 87$) were aware of resources than physicians in urban practice areas (70.9%; $n = 90$), $X^2(1, N = 243) = 0.52, p = .47$. For gender, men (74.0%; $n = 92$) reported a similar level of awareness of local resources as women (72.2%; $n = 83$), $X^2(1, N = 231) = 0.36, p = .55$.

With regard to access to screening and diagnostic services for patients, overall, 156 (64.2%) of the physicians reported that they were able to access these services. Results of chi-square analyses revealed statistically significant differences for medical specialty. Pediatricians reported the highest level of access to screening and diagnostic services (88.5%; $n = 54$), followed by 57.6% ($n = 19$) of OB/GYNs, and 55.7% ($n = 83$) of family physicians, $X^2(2, N = 243) = 21.0, p < .00$. Although non-significant, some slight variations were present with regard to other physician characteristics. More male physicians (64.8%; $n = 81$) were able to access services than female physicians (64.3%; $n = 74$), $X^2(1, N = 231) = 0.38, p = .54$. Physicians working in a Native health corporation had the highest percentage of respondents reporting access to services 75.9% ($n = 41$), followed by 66.7% ($n = 24$) of physicians working in other settings, 59.8% ($n = 79$) of physicians working in private practice, and 57.1% ($n = 12$) of physicians working in a hospital, $X^2(3, N = 234) = 6.83, p = .08$. Physicians practicing in urban communities (64.6%; $n = 82$) were more likely to be able to access screening and diagnostic services than rural practice physicians (63.4%; $n = 74$), $X^2(1, N = 243) = 0.16, p = .90$.

Effects of gender, medical specialty, practice location, and work setting. To assess the relationship between physician characteristics and perceptions about access to FASD diagnostic and screening services, as well as general FASD-related resources for patients, two logistical regressions were performed with gender, medical specialty, practice location, and work setting as predictor variables. For the two analyses, the criterion variables included physician responses to the following questions: 1) are you aware of FASD resources in your community (yes and no), and 2) do you have access to FASD screening and diagnostic services in your community (yes and no). The factorial logistic regression analysis of awareness revealed no significant overall model effect, $X^2(26, N = 233) = 33.85, p = ns$. However, a significant independent variable effect of medical specialty was revealed, $X^2(2, N = 233) = 5.78, p < .05$. Pediatricians reported a higher level of awareness of FASD-related resources than the other two medical specialty groups, namely, family practice physicians and OB/GYNs. The factorial logistic regression analysis of screening and diagnosis revealed no significant overall model effect, $X^2(24, N = 171) = 31.20, p = ns.$, and no specific group effects.

Effects of age, years of practice, and patient load. Using a logistic regression analysis, relationships were explored between the predictor variables of age, years of physician experience, years of experience in Alaska, and number of patients served per week and the criterion variables of awareness of resources (yes and no) and access to screening and diagnosis (yes and no). The logistic regression of awareness revealed no significant overall model effect, $X^2(4, N = 206) = 2.46, p = ns.$, and no specific group

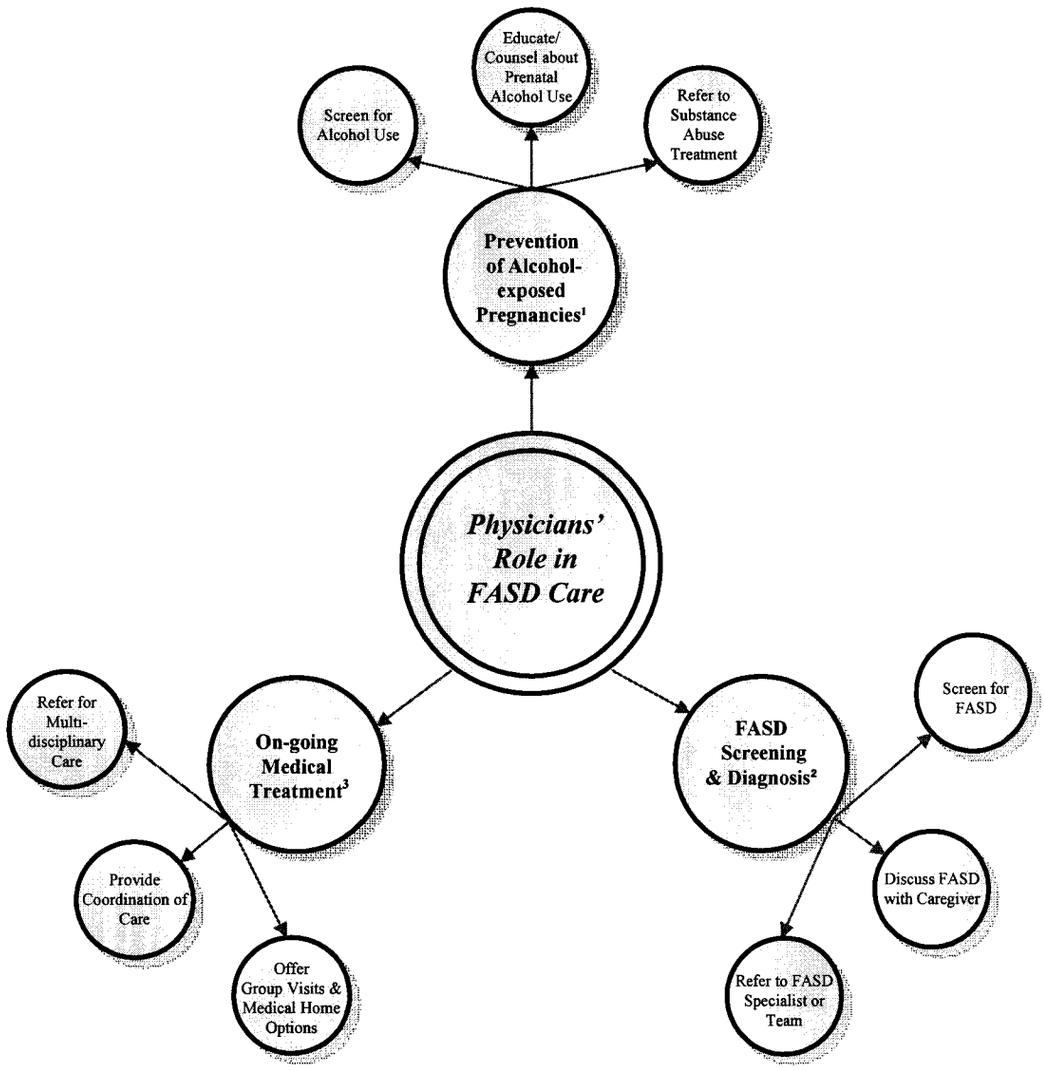
effects. The logistic regression analysis of screening and diagnosis also revealed no significant overall model effect, $X^2(4, N = 151) = 4.20, p = ns.,$ and no specific group effects.

Chapter 5 Qualitative Research Findings

Based on qualitative analyses of the key informant interviews, a number of themes emerged as physicians discussed provider practices related to FASD prevention, intervention, and treatment. More specifically, through free coding of the 24 interviews, 14 individual nodes emerged from the data that were thematically sorted into four broad categories, described as *Physicians' Role in FASD Prevention and Care*; *FASD Practice-related Barriers*; *FASD Service, System, and Training Gaps*; and *Other Factors Influencing FASD Prevention and Care*. The presentation of qualitative results that follows is organized along the structure of these four overarching themes.

Physicians' Role in FASD Prevention and Care

As a main focus of the interview, respondents shared information about their roles as a physician in FASD prevention and care, as well as insights into their current FASD-related medical practices. Figure 7 offers a visual representation of the qualitative themes that emerged in the broad category entitled, *Physicians' Role in FASD Prevention and Care*. The following section provides a detailed summary of the results inherent in each theme within this category. The themes include *FASD Prevention, FASD Screening and Diagnosis, and FASD Ongoing Medical Care.*



Note: ¹primary prevention, ²secondary prevention, and ³tertiary prevention

Figure 7. Physicians' Role in FASD Prevention and Care

FASD prevention. In general, physicians expressed that within their professional work they have a responsibility to screen for alcohol use by female patients, educate and counsel them about the consequences of consuming alcohol during

pregnancy, and refer them to treatment, if needed. Comments included:

> It's about taking a lifestyle habit history either as part of well woman care in discussing family planning or during that initial prenatal visit...asking about whether people normally drink, whether they [drank] before they knew they were pregnant, and if they're currently drinking now while they know that they are pregnant. And then discussing with them about the risks of drinking during pregnancy.

Physicians identified OB/GYNs and family practice physicians as having more frequent opportunities to address FASD-related prevention with women, stating: "Family physicians and obstetricians have a huge role in prevention, making sure that women know that no amount of alcohol is safe in pregnancy and conveying that message, which is not always done."

With regard to screening for alcohol use by pregnant women and women of child-bearing age, 11 physicians noted the importance of practicing universal screening by means of verbal questioning, written questionnaire, or self-report alcohol screening tool (i.e., CAGE: Cut down, Annoyed, Guilty, and Eye-opener). One physician stated:

> It helps me in our clinic when we ask those questions, in that if they're already in the questionnaire and I can just look down the questionnaire really quickly and see okay, which column have they marked in that I need to address? We see that they're flagged because they're in the 'yes' column and then we think 'oh, okay, so I need to ask them more about this.' So to me that saves a lot of time if

> you have people filling out questionnaires, whether they do it online at a computer or whether they even do it just manually on a piece of paper.

In addition to being a time-saving strategy, the use of questionnaires helps physicians develop a baseline for alcohol consumption prior to pregnancy and monitor use over time. One comment was:

> What we do at our clinic is everybody who walks in the door...our medical assistant asks them do they smoke and use alcohol. I think that's a screening point that we use to try and identify women. For women, it seems like in their child-bearing years if we can even first ask the question "how much do you drink?" If they do become pregnant, we've at least maybe gone part way in identifying people who might be at risk for giving birth to babies affected by fetal alcohol.

Regardless of screening method, seven physicians shared that it is very important to consider the patient-provider relationship when assessing alcohol use and counseling patients about the use of alcohol during pregnancy. Comments included:

> It's important that physicians have a relationship with their patients that allows them to be more open. I try to spend a lot of time with patients, talking about their lifestyles. I think the relationship you develop with the patient helps you to pick up on what they're doing with alcohol and other drugs.

Key components that were noted as making the relationship effective included sensitivity, trust, and lack of judgment. One physician shared this sentiment in the

following manner:

> Just how a sentence is phrased can make a big difference, but so much of it too is just the tone of questioning, but non-verbal too. When a woman is pregnant, her relationship with her provider is so important and the trust has to be there. If a woman knows from previous interactions that she might potentially be judged negatively, she might never say that she uses alcohol at all. Then you're stuck because you don't even have a place to start. Having a relationship where a patient can be open and truthful without being judged is an important starting point.

Moving beyond the manner in which physicians screen for alcohol consumption by women, respondents also shared how important it is to educate women at an early age and frequently about FASD prevention:

> A lot of times women are young and healthy and they don't come in until they are already pregnant....trying to capture the population of women who are in childbearing age range, even if they're young and healthy to come in annually at least and get their other preventative healthcare.

One opportunity mentioned by two physicians regarding educating women at an early age was in conducting high school physicals:

> You talk to them about if they are sexually active or if they are thinking about it and what they are doing to prevent getting pregnant if they're not ready to. And then when they do become pregnant, smoking and alcohol are both bad things.

> Taking your vitamins is a good thing, a good diet is a good thing, getting regular prenatal care is a good thing.

Several opportunities for educating patients outside of prenatal visits were reported by physicians. These included, but were not limited to, the following types of medical visits: annual exams when getting pap smears and breast exams, pre-conception counseling visits, sexually transmitted disease screenings, and contraception visits. These educational opportunities were illustrated in the statement by one physician that "if they get their pap-smears and breast exam, that's when you can bring up alcohol use every time. So ideally you're going to catch a lot of these women before they even get pregnant." Another physician commented:

> Education during pregnancy and preconception is probably essential in the context of prescribing birth control, doing STD testing, all that kind of stuff. So it seems like it needs to have a key place at that point. Education as part of the visit for adults or women who could potentially become pregnant.

Approximately half of the 24 physicians noted promising practices, including the use of behavioral specialists and groups visits, to improve the effectiveness of education efforts. One physician shared the following example:

> Pregnancy would be a great place to be doing [group visits] where women who are early in pregnancy have an option to come to a group type of setting where they're seen by a physician, an educator, and maybe a nurse who could really take people aside and screen with and stratify them and really ask them those

tough questions and educate them in a non-threatening way.

Physicians reported that the main educational message they provide to women is *"no alcohol during pregnancy is the only safe amount."* Eight of the 24 physicians reported the need to be "*blunt*" with this message, stating clearly to women that alcohol will affect the wellbeing of their unborn child. One effective educational message communicated to women of childbearing age by a physician respondent was: "There is good evidence even a small amount of alcohol can cause problems to your baby in pregnancy. There is risk of potential alcohol impact even really early in pregnancy."

For women who experience alcohol abuse or dependence, physicians described their role as going beyond that of educator, moving into the role of referral agent for substance abuse treatment. "It's like a medical emergency when you find out someone is a substance abuser in pregnancy—not only about what has already been done, but what can still happen." In this situation, physicians viewed their roles as supporting the pregnant woman in maintaining her sobriety by providing treatment referrals. This was illustrated in the following physician statement: "Get them into a counselor; get them into some support group, something like that. It's better than nothing, than just letting them flounder on their own and ending up with a disabled kid." A small subset of five physicians shared that pregnancy was a time when women were contemplating changes; therefore, they may be more open to beginning treatment. One stated:

> I still think pregnancy is such a change opportunity because women so often can't do it for themselves but they can do it for their babies. You'll see that a lot

where they'll stop smoking and then the day after delivery they light up again. But again we can do that too with alcohol.

FASD screening and diagnosis. Physicians identified themselves as playing an important role in FASD screening and diagnosis. With regard to screening, 13 of the 24 physicians shared that they have a unique opportunity to identify children at an early age through initial neonatal assessments and periodic well-child examinations. They expressed the belief that these medical appointments allowed them the opportunity for early identification through a routine medical examination process.

> When the baby is born, it's important to do a very careful physical examination. You want to look for microcephaly. You want to look for any facial features of FAS. See if you note anything that's suggestive of FAS. And then make sure that the child gets good, routine, well-child care and, at each of those visits, do a careful developmental screen. That often is -- when the kids start falling behind developmentally is when it starts becoming clear that they are somewhere in the FASD spectrum.

Although they viewed their role as important in conducting screenings for FASDs, one-third of the physicians shared that given the physical characteristics, it was much easier to screen for FAS than for disorders that fall elsewhere on the spectrum.

> Severe fetal alcohol [syndrome] is a little easier when it comes with actual physical characteristics consistent with the diagnosis. I think it's much harder when there is more subtle prominently cognitive and less physical features.

There are criteria that have been somewhat standardized of the physical features.

Inherent in the FASD screening process was the need to communicate with caregivers not only about whether prenatal alcohol exposure occurred, but also about the need to consider a diagnosis of FASD. This conversation was viewed as another responsibility that was an integral part of physician screening services around this health issue. Over half of the physicians noted that this was often a difficult conversation to initiate. One stated:

> I always review the mom's record and see if she has been drinking and talk with her too and just ask her: "were you drinking at all during the pregnancy?" Almost invariably, I hear, "No, not at all, of course not." So, I can get a sense for has this kid been exposed or not and have a good sense of if the person is being honest with me.

Although this process was difficult, one physician shared an effective approach that could be taken by a medical provider:

> When it's [FASD] suspected, work with the family in a positive way to help them be able to accept the fact that we are thinking about this, we're really unsure of it and that's usually the case with FASD because most of them don't fit the textbook picture…You want to do physical and other examinations to figure out what behavior or developmental problems may be occurring that would suggest that's what it is.

Physicians also spoke about their roles and responsibilities related to conducting

FASD diagnoses. In this FASD practice area, physicians viewed their role as dependent upon their level of expertise. If they were experts and worked within an FASD diagnostic team setting, rendering a diagnosis was considered within their realm of professional practice. If they did not have the expertise and did not work within a team setting, their role was that of discussing the possible diagnosis with patients or caregivers and referring them to an FASD expert or an FASD diagnostic team. This belief was communicated in the following physician's statement:

> I really do feel like children have to be seen by someone who is experienced in the diagnosis. I can diagnose young children if they have all the features, but for the most part unless you're full blown it's fairly subtle and physical features are not that helpful. You need to know about their brain which is not something you can do in an office visit. It's so much more complicated. So the diagnostic team I think is essential in being able to get an accurate diagnosis.

All physicians discussed the importance of referring patients and caregivers to providers who have expertise in the FASD diagnostic process. Most commonly physicians discussed referring patients to pediatricians with FASD expertise or FASD diagnostic teams. Prior to referring the patient, physicians shared the importance of completing a thorough evaluation to rule out other disorders. One physician explained the referral process in the following manner:

> As a family doctor it's really not unreasonable for me to say, "I think this is the diagnosis based on this and this and this, but this is a situation where I think it'd

> be really nice to get an expert opinion from someone who really has taken some time to learn more about this disease and see what they think and get another brain to think about it." Then once that diagnosis is confirmed, it's not something I'm afraid of taking care of. But it's really nice to have somebody else have looked over everything and make sure there's not something I'm missing.

As noted in Chapter 4, physicians generally were aware of the existence of FASD multidisciplinary diagnostic teams in Alaska. One component of the diagnostic teams that they viewed as significant was the involvement of other disciplines in the diagnostic process, as a means to gather a full range of diagnostic information. One comment was:

> I think that the best diagnosis of FAS is a team approach. Physician can play a part in that, but I think that there is also psychological evaluation, social and emotional evaluation -- I think a multi-disciplinary approach is the best way to go about it. It's incredibly difficult. There is no way to just objectively do a test and diagnose someone with FASD.

FASD ongoing medical care. In addition to their roles in the prevention of FASDs and provision of FASD screening and diagnostic services, physicians discussed their role in maintaining long-term medical care for individuals experiencing FASDs. Generally, physicians shared that patients with FASDs are treated no differently, medically, than other patients experiencing physical disabilities; and treatment for

physical disabilities required additional physician time and care coordination to achieve adequate ongoing care. One comment was: "To be honest with you, for kids who have some type of diagnosis within the spectrum of disorders, I don't really follow them any different than my kids who have significant developmental delays or behavioral problems." As physicians shared, the use of a generic process for providing medical care for FASDs is occurring because there are no "special" medical treatments for this set of disorders:

> In recognizing there's no specific treatment for it [FASD]... it's really a matter of supporting the child's needs. And I think the role of the physician is to be a care coordinator and to help parents access the different types of services they need both for school and therapies, as well as support.

Eighteen of the physicians identified care coordination as a vital service they provide to patients and their families in the treatment of FASDs. Respondents discussed that this level of care coordination required several steps, including: 1) assessment of the individual's needs; 2) identification of medical specialists (i.e., developmental pediatrician, psychiatrist), other health providers (i.e., occupational therapist, speech and language pathologist, mental health counselor, social workers, parent advocates), or programs (i.e., infant learning program, special education, parent support groups); and 3) maintenance of communication with providers to assess progress. One physician described care coordination and its value in the following manner.

> Get them access to services as early as possible, both for the child getting occupational therapy, speech therapy, and physical therapy, whatever kind of therapy they need. Getting them into the developmental preschool program once they hit three, those are all really important. Also, offering the mother support because these are mothers with young kids who often become pregnant again. It's important to try to work on keeping them sober so that there's [sic] not multiple kids in families.

In combination with care coordination, approximately half of the physicians discussed the possibility of using newer medical practice methodologies in treating FASDs. Two ideas that were mentioned by physicians were group visits and medical homes. A group visit was discussed as an alternative to a one-on-one visit in which the physician would work jointly with a nurse or behavioral health specialist to educate and provide care to individuals and families dealing with a diagnosis of FASD. A medical home was viewed as a means to enhance the care coordination process and an ideal method of care by six respondents. The following statement was one physician's definition of a medical home.

> The medical home is the place that makes the referrals and coordinates and tries to help interpret and help the family really stay connected so we have the idea that it's family-centered care and the family is as much in charge of it as the physicians and the specialists, but that's a lot easier said than done.

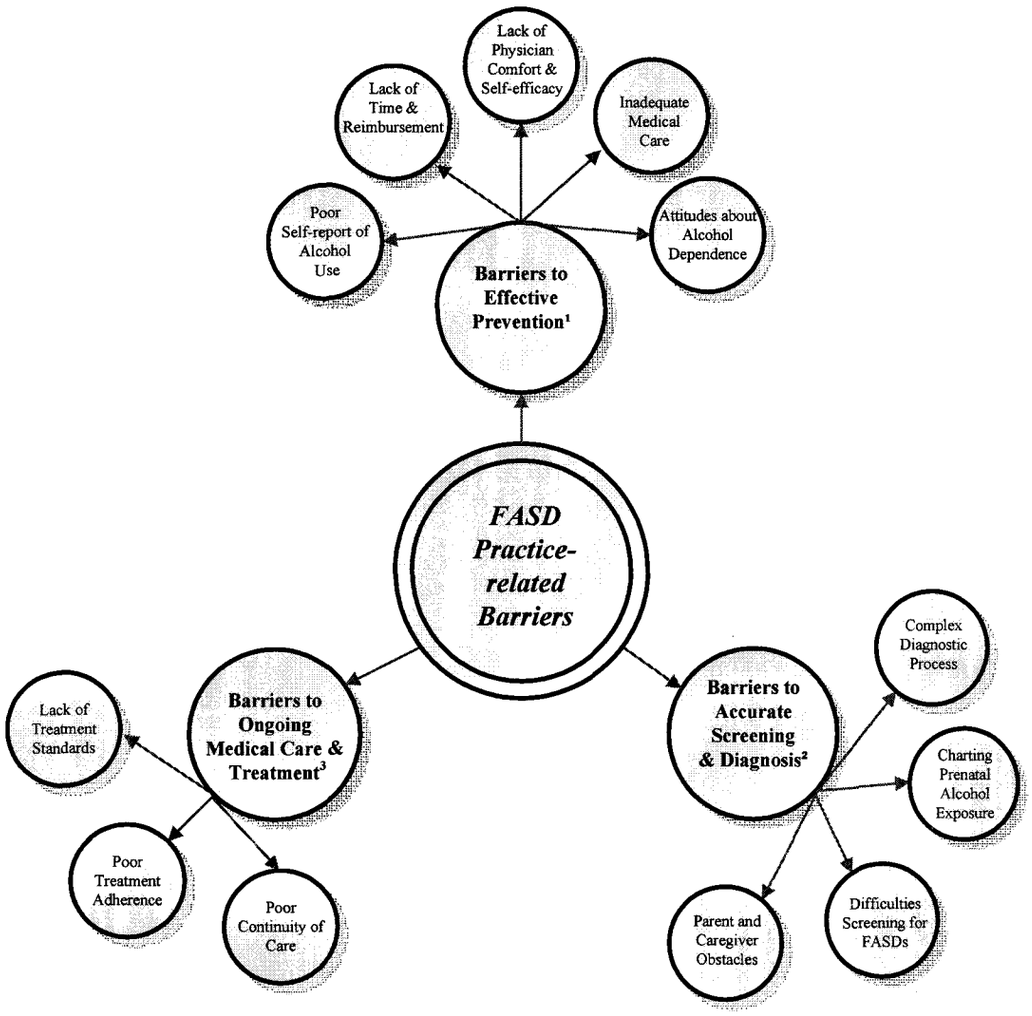
A few physicians reported that they serve as medical homes for patients experiencing

FASDs. For example, one physician provided a case example of serving as a medical home for two children with FASDs.

> I'm thinking now about two children we have seen in our office. All of us have seen them, but they really got into our practice and we became their medical home only after they were placed in a foster home. In their situation, the problems of neglect, and in one case abuse, were probably more severe than the problems of fetal alcohol effects. We're pretty sure about the diagnosis of this because the parents have admitted that there was a lot of drinking during their pregnancy. But the thing I'm citing here is a way to change attitudes about this -- these two children were very fortunate to have very experienced foster families, not just parents but the family. The children of the foster parents, their natural children, welcomed these children just like they were their own brothers and sisters. We also were providing catch up work on medical needs; much better nutrition, and so forth. To watch the progress these two children have made, they were both referred to our infant learning program and they've got a much better prognosis. If this had gone on for five more years, these kids were that much older and living in that neglectful, sometimes emotionally hostile situation, the ability for those children to heal and to have a better outcome. So what I'm really saying is the sooner you recognize it and you act on it and you provide some real services for it, the better the outcome is going to be and the idea that it's hopeless will eventually fade.

FASD Practice-related Barriers

During the interview process, physicians identified barriers that interfere with their ability to provide optimal FASD-related medical care. Figure 8 offers a visual representation of the qualitative themes that emerged in the broad category entitled *FASD Practice-related Barriers*. The following section provides a detailed summary of the results inherent in each theme contained within this category. These themes include *Barriers to Effective Prevention, Barriers to Accurate Screening and Diagnosis, and Barriers to Ongoing Medical Care and Treatment.*



Note: ¹primary prevention, ²secondary prevention, and ³tertiary prevention

Figure 8. FASD Practice-related Barriers

Barriers to effective prevention. Nineteen of the physicians identified the underreporting of alcohol use by women of childbearing age and pregnant women as a major barrier inhibiting their ability to use primary prevention strategies proactively to reduce alcohol-exposed pregnancies. If physicians are not aware of or do not know the

extent of alcohol use by their female patients, they cannot put FASD prevention as a priority within a medical visit. One physician captured the difficulty with assessing alcohol consumption in the following statement.

> Usually, they're in denial. Sometimes they're straightforward. Sometimes they realize "yeah, I'm drinking too much and it's an issue," but I think more often than not women don't tell you the level of their consumption. You maybe have some suspicions, but it's difficult to confirm it one way or the other.

Physicians described it as a challenging task to encourage women to disclose their alcohol use and to help them understand if their use went beyond moderate levels, causing health-related and other life consequences. One comment was:

> When they say they drink socially, they're serious. They drink socially. They don't feel that they really have a problem. In reality, they are actually drinking way more than they ought to be. Trying to figure out if people are being honest with you or not and if they're being honest with you, are they being realistic is difficult.

Some physicians believed that discussing alcohol consumption was a sensitive process and, unfortunately, could be influenced by a lack of trust in the medical system. One commented:

> Women in families who do drink to excess, by and large, are untrusting of the medical system. The other thing is that denial is big and women who are drinking don't want you to know, often times, because they're worried that

> [government agencies] will get involved or somebody will come in and disrupt their life, make it harder.

Fear of possible outcomes related to the disclosure of alcohol use by pregnant women was one reason why physicians thought women did not give an accurate self-report of alcohol use. The poor self-reporting of alcohol consumption is unfortunate as accurate information in this regard would open the door for education about and support to women in reducing prenatal exposure to alcohol.

Twenty-one of the physicians stated that lack of time and lack of reimbursement were barriers for providing comprehensive primary prevention practices. These barriers were identified not just for FASD prevention, but for prevention practices related to health issues in general. One stated:

> In an era of declining reimbursements, providers are forced to see higher volumes of patients and just basically stay on the problem-oriented visit, the tertiary level, rather than at the primary prevention level. It takes additional time to address tobacco cessation, exercise patterns, substance abuse....each one of those could take an hour.

For example, family practice physicians reported needing to screen for increasing numbers of health conditions, requirements that take time and reduce reimbursement per appointment. The consequence of being overextended with screening responsibilities was explained by one participant in this statement: "I think sometimes choices are made about what to screen for. It's trying to I think balance the amount of

information that you're trying to get from a patient with what you're going to do with it too." Deciding on the focus of a medical visit can be complicated in that the priorities of a visit are often dictated by the amount of time, type of reimbursement, and patients' own reasons for seeking medical care:

> There are so many things to do in a given period of time with a patient and people probably have different priorities, and I would think this would be their highest priority topic, and sometimes maybe this falls low on the list.

Over half of the physicians reported a lack of comfort and low self-efficacy in addressing alcohol use and abuse issues in their efforts to prevent alcohol-exposed pregnancies, as well as when exploring prevention as related to general alcohol consumption issues. Conversations around drinking alcohol during pregnancy were viewed as important, but difficult and often perceived as less than successful due to patients' resistance to openly discuss and consider changes vis-à-vis alcohol use. One statement was:

> It is a tough conversation. Labeling somebody's personal choices as "bad" is difficult because we all make choices. We all do things that probably aren't the best, but being able to say to someone "no, you can't do that...that's not good"... it's hard.

Physicians shared that alcohol consumption is an especially challenging behavior to address because alcohol is a legal substance:

> It is easier if it's something like say an illegal drug. It's easy for that to be able

> to say "yeah it's illegal for a reason." Some physicians have a hard time saying "you need to make good choices and this isn't a good one."

Three of the physicians described themselves as "outsiders" in their patients' lives. As outsiders, they were uncertain about their ability to understand what a woman was going through and about how to support her in making significant behavioral changes in her life, particularly as related to addictions. One stated:

> Very few people will let you in. They're hurting so bad inside that whatever is driving them to drink is more important than the baby inside them and they are going to drink. Not every patient lets you empathize with them and some are kind of there only under duress. It reminds you how futile some of those attempts are.

Training about how better to communicate with patients around sensitive issues was identified as lacking in physicians' education and viewed as challenging to master without specialized guidance.

Twelve of the physicians identified lack of optimal prenatal care as a barrier to providing universal primary prevention for reducing alcohol-exposed pregnancies. To provide effective primary prevention to patients, physicians would need to have access to pregnant women early in gestation. Unfortunately, physicians reported that in Alaska prenatal care is neither accessible to nor sought out by all women. Even when women do seek out prenatal care, the first prenatal visit typically occurs toward the end of the first trimester. This barrier was summarized in this physician's statement: "Prenatal

care providers do not see patients until after 12 weeks to make sure the pregnancy is viable, because a fair number of pregnancies will actually spontaneously miscarry and the first prenatal visit is actually pretty resource intensive."

Five of the physicians presumed that women at greatest risk for giving birth to a child with an FASD were women who were least likely to seek out preconception counseling and prenatal care: "I think one of the big barriers initially is because of the nature of substance abuse. Often times these patients aren't going to be seen early when we could really do some proactive prevention." Another factor contributing to screening challenges was the perception that patients who have substance abuse issues are more likely to seek care from providers who do not conduct alcohol use screenings and are unlikely to communicate the dangers of alcohol consumption during pregnancy. One comment was:

> Something that happens in people who are tending to use substances is they sometimes select providers who may not be as active about asking questions about what they're doing. And the word gets out that if you go to this person they won't ask you any of these questions. I think the best way to handle that as a system would be that we really need to do some kind of screening early on all pregnant patients.

Speaking about the challenges in reaching pregnant women, one physician shared that "there's a huge population that's choosing not to use birth control who's also not seeing a provider." These women were perceived by physicians as outside of

their reach; they simply expressed hope that other professionals were addressing the issue of FASDs with this group:

> Particularly the pregnant women who are most at risk for exposing their fetus to alcohol are the ones that are least likely to be getting early care and good care. I don't think physicians in general are in a great position to be the primary education source.

Seven physicians shared that the manner in which alcohol dependence was viewed within their profession could serve as a barrier to addressing and preventing FASDs effectively. Although physicians reported that they believed pregnant women did not drink with the intention of harming their fetus, they questioned whether alcohol dependence was a physical disease or a moral deficit. For example, one physician stated:

> In the experience I've had, even if they are drinking there is some level of concern for the baby. I mean there are some people who have no concern and will continue to drink or do drugs because they're not rationally minded. Their perspective is altered.

Physicians noted that the way alcohol dependence was viewed played a role in how the issue was addressed with patients. One physician summarized the issue in the following manner:

> In terms of physicians in general having a consistent message and a persistent message, I think the problem is that some physicians don't believe they're

> [chemical dependencies] diseases. They think they are character flaws. I think there's a subsection of physicians that are really codependent about the whole thing and they blow it off. So that kind of destroys the consistency and the persistence of the message.

In conjunction with concerns about misperceptions about alcohol dependence, physicians reported a sense of feeling powerless vis-à-vis preventing prenatal alcohol exposure. This sense of futility was, in part, attributed to physicians' beliefs that they had no concrete or tangible intervention that could help stop a pregnant woman from consuming alcohol. One respondent expressed this frustration in the following statement:

> They're pregnant, they're drunk, they're in the hospital for one reason or the other, and basically, until a child is born it has no rights in the state. So they can kind of drink all they want, and whether it's bad or good, whatever problems that are leading them to do that, you can't really derail that sometimes. You don't have any ability or power to stop that when you see it happening sometimes, and that's frustrating.

Although several physicians acknowledged a sense of powerlessness, a subgroup of six physicians had a contrasting perspective. This perspective addressed how accepting a disease model related to alcohol dependence provided a better opportunity to intervene and reduce the consequences of prenatal alcohol exposure. For example, one physician made the following statement:

> They don't put it in a disease framework and so they aren't being therapeutic about their interventions. If they're blaming then it's not a therapeutic relationship. They should be saying, "This has some consequences. There are things we can do for you. If you can't stop drinking on your own, we have treatment; we have outpatient treatment; we have inpatient treatment; and you get a priority because you are pregnant."

Barriers to accurate screening and diagnosis. A number of themes emerged as physicians discussed barriers related to FASD screening and diagnosis. Although physicians acknowledged the importance of their role in screening for FASDs and referring for diagnostic assessments, physicians shared that their ability to screen individuals accurately for an FASD was inhibited by the lack of a standardized system for documenting prenatal alcohol exposure in the charts of newborns. One statement was:

> Unfortunately, that is not a standard part of the child's paperwork on leaving the hospital, so as a result it becomes much more difficult to find actual documentation and quantification of the alcohol use. I think that if we had something that was very standard like that, it would make the whole process much easier.

Another barrier physicians discussed related to FASD screening was the challenge of not feeling confident in their ability to make appropriate referrals for diagnosis. They noted that it was especially difficult to identify clinical triggers that

prompt a diagnostic referral when facial malformations and physical criteria are absent. This barrier was exemplified by the following physician statement:

> What happens is that the potential diagnosis of FASD is often overlooked. You have children and adults who may present predominantly with some mild learning disabilities and behavioral problems, without the facial features and growth issues. They have the behavioral problems addressed, but the underlying diagnosis of FASD is never considered.

Over half of the physicians acknowledged that they did not diagnose FAS or FASDs as part of their practice. For formal diagnostic evaluation, most physicians reported referring patients to an FASD diagnostic team or a physician who specializes in FASD. They identified multiple barriers inhibiting their ability to perform diagnostic evaluations for FASDs and to access diagnostic services for their patients. First, physicians viewed the diagnostic process as ambiguous because "there is no way to just objectively do a test and diagnose someone with FASD." Although FAS has set criteria for diagnosis, disorders falling elsewhere on the spectrum do not have equally clear diagnostic guidelines. Almost all physicians were aware of the University of Washington 4-Digit FASD Diagnostic System and its use by the diagnostic teams in Alaska. However, within their own practice, they viewed this system as "very complicated and fairly impractical for use in general medical settings."

Second, physicians reported that to arrive at a truly accurate diagnosis they needed access to results of assessments from other professionals, such as

neuropsychologists, occupational therapists, and speech and language pathologists. Without such assessment information, physicians were concerned that they would not be able to make an accurate diagnosis, and therefore they were less likely to give a formal diagnosis. Overall, physicians who had not received specialized FASD diagnostic training discussed concerns about providing this diagnostic service:

> I don't want to make a mistake and mislabel a child with FAS because then the parents are constantly going to look at this child who has FAS even if the child never really had it and I made a mistake. I would feel horrible! You don't want to mislabel a child and miss a diagnosis and do the wrong thing.

Eleven physicians shared that another barrier to FASD screening and diagnosis was the challenge of engaging parents and caregivers in the process. Physicians identified a lack of routine pediatric care for all children as a barrier to physicians' ability to conduct FASD screening and diagnostic referral. Physicians shared concerns and challenges related to families and caregivers being reluctant to recognize the effects of prenatal alcohol exposure on a child or family member. One stated:

> They don't come to us regularly, they don't really trust doctors, nurses and clinics. When we see that there's a possible problem, we try to deal with it but often scare them off. We know we're clearly missing some because they just don't want to face it.

Half of the physicians reported that dealing with emotional reactions and fears of parents or caregivers was very difficult and the manner in which this was done could

either improve or hinder the likelihood of follow-through with the diagnostic process. For example, one physician stated:

> I think the harder problem is if a person brings their child in for issues, recognizing it and then you point-blank ask them, "Did you drink during your pregnancy?" You're starting to point the finger at them and that destroys the patient-physician relationship. You want to be on their team and help them, but at the same time you're trying to collect information that might point the finger at them.

Finding a means to support families in overcoming barriers to getting a diagnosis was viewed as extremely important:

> There's a great deal of fear and how to overcome that is the biggest challenge. We just have to communicate that the first solution to any medical problem is an accurate diagnosis and, hopefully, gain their trust so that they will become involved.

Barriers to ongoing medical care and treatment. When physicians discussed barriers that impinged on their ability to provide adequate ongoing medical care for individuals experiencing FASDs, three main concerns emerged. These included the lack of standardized treatment protocols for providing ongoing medical care to individuals experiencing FASDs, problems in establishing a continuum of care for individuals experiencing FASDs, and trouble providing medical care to individuals with FASDs due to their difficulty adhering to medical recommendations and treatment

plans.

In their work with most medical conditions, physicians were trained to diagnose health problems and develop treatment plans that help alleviate or heal problems. In the case of ongoing treatment for FASDs, all patients are unique and treatments need to be tailored. Physicians shared that the lack of a standardized approach to treating FASDs across the lifespan was a source of frustration and led them to feeling less than effective in tackling this complex disorder. For example, one physician responded to the question about barriers to ongoing care with this statement:

> Yeah, we know how to take care of hypertension and chronic receptor pulmonary disease. I don't know how to take care of FASD. That's really frustrating. We're here to try to fix things...that is what we get paid to do...but FASD you don't fix.

A subset of eight physicians reported that it was difficult for individuals with FASDs to secure consistent, ongoing medical care throughout their lives. This difficulty was in part due to the need for treatment from different medical specialists across time. As one physician stated,

> Often what happens is that you switch providers. OBGYNs don't do pediatrics; pediatricians don't do deliveries; and family medicine does both. Unfortunately, there isn't a standard mechanism [in place] to make a diagnosis that will carry on with the child to support adequate care throughout life.

Physicians also reported that patients with FASDs required more time and

resources to assure they were getting the full continuum of care needed for the best outcomes. This was referred to by some physicians as serving as a "medical home." Physicians stated that it was difficult to identify needed referrals, secure services for patients, and manage outcomes of these services across multiple providers. This complexity of care coordination was expressed in the following statements:

> You get into the issue of how do you find resources to help the family in the community. We certainly don't have all the resources we really would like to have for this and we try to do our best to deal with it. There are wait lists and the inability to communicate directly from professional to professional. I can't get on the phone with a behavioral health professional and talk to them directly very easily because they're busy seeing people.

With regard to the experience of providing ongoing medical care to individuals diagnosed with FASDs, physicians shared that they often struggle with helping this patient population to understand their health status and follow medical regimens and recommendations. This frustration was expressed by one physician in this manner:

> I probably do more than the average family practice doc, in making sure people get things done. But you don't have the time or luxury to coddle or hand-hold people to make sure they get that ride or get everything all lined up to make it across town to see the provider.

FASD Service, System, and Training Gaps

Throughout the interview process, physicians identified gaps in services,

systems, and training and education that affect their FASD-related medical practices. Figure 9 offers a visual representation of the qualitative themes that emerged in the broad category entitled *FASD Service, System, and Training Gaps*. The following section provides a detailed summary of results inherent in each theme contained within this category. The themes include *Service Availability and Accessibility Gaps, Providers and Referral Shortages, Training and Education Gaps, and Gaps in Rural Alaska Communities.*

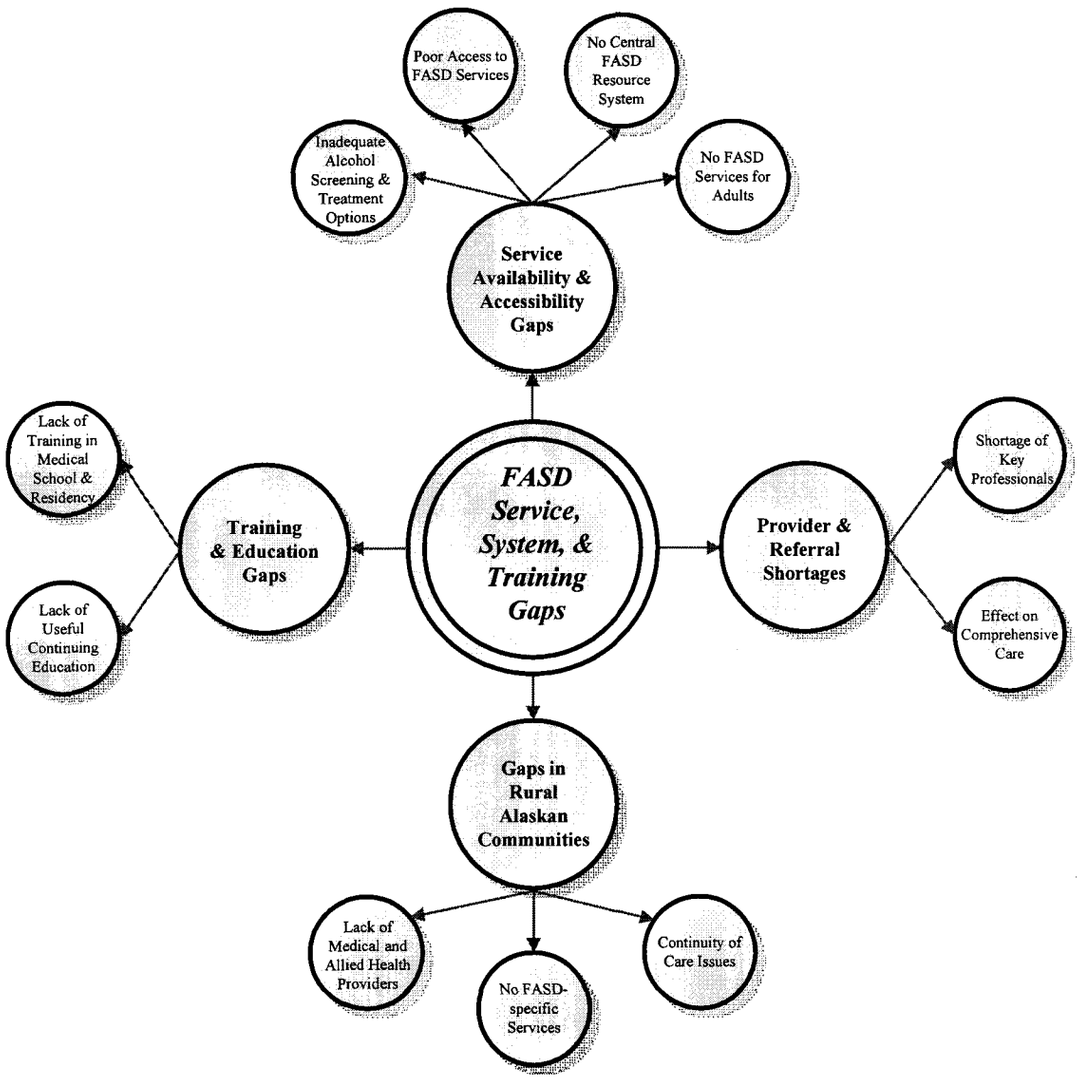


Figure 9. FASD Service, System, and Training Gaps

Service availability and accessibility gaps. All but two of the physicians spoke about how limited availability of and access to needed resources hindered their ability optimally to address FASD prevention, diagnosis, treatment, and long-term care. Beginning with FASD prevention services, physicians noted the importance of

universal alcohol screening for women of child-bearing age and the general need for women's health screening systems as a routine component of healthcare. Although recognizing the importance of screenings, physicians were less than confident that screenings were an actual regular practice in all medical settings and by all healthcare providers. All but two physicians expressed the opinion that OB/GYNs and family practice physicians were best positioned to conduct alcohol and FASD screenings. They noted that screening could be better accomplished through a healthcare system that reimburses and supports the integration of behavioral health professionals into routine care:

> Just screen everybody for domestic violence, drug and alcohol use, screen for a bunch of risk factors at the appointments. And it would be cost effective too because preventing all sorts of sequelae. But I think that would be the way to go. I've just found behavioral health to be so helpful in the clinic.

In combination with the desire for universal screening and support from behavioral health specialists, physicians reported that helping their patients abstain from alcohol was complicated by insufficient substance abuse treatment services in Alaska, including alcohol detoxification and inpatient and outpatient treatment options. One physician stated:

> We put all this money into the criminal system in incarceration, what percentage of those people are substance abusers and have mental health issues and they're basically caged rather than treated. So this whole area is underfunded and it's

not unique to FASD. Although it obviously is transgenerational, children are born with these fixed deficits.

Thirteen of the physicians discussed concerns related to their inability to access diagnostic services for patients once they have screened for FASDs and identified a need for further evaluation with an FASD diagnostic specialist. Although most physicians were aware of the existence of FASD multidisciplinary diagnostic teams within the state of Alaska, many reported difficulty referring patients for a diagnosis due to the non-existence of a team in their community, uncertainty about referral processes and criteria, and concerns related to long waitlists and low diagnostic capacity. As one stated,

> In fact it's one of the issues in terms of the services available is that all of our diagnostic teams in the sense that they still exist are overwhelmed, we get these long waiting lists. It is labor intensive to do these evaluations.

Two additional concerns were voiced about the long-term benefits for patients who participate in the FASD diagnostic process. First, within the Alaskan model, diagnostic teams are tasked with rendering a diagnosis, not developing a long-term treatment plan or tracking outcomes. Thus, once a diagnosis has been rendered by a diagnostic team, the team disseminates its findings and essentially ends its contact with the patient and family. One physician expressed it this way:

> I kind of feel like the diagnostic teams were great, but I feel like we're not making any progress because we're not following these kids and finding out if

this diagnostic process is working, is helpful, is meaningful for their future. Second, although physicians appreciated the option of referring to a diagnostic specialist outside of their community, some reported that it would be more supportive to the patient to have a professional familiar with services available within the patient's community to suggest referrals and follow-up services for the individual and family over time:

> When we see a kid from [rural community], we don't know that community, we don't know what's going on in that community and they need to be evaluated in their own community so that they can be linked to the appropriate services.

With regard to specialized treatment programs and other FASD-related services, nearly all of the physicians reported not being aware of them and having concern that these services did not exist for their patients who experience FASDs:

> If the information is out there and we can develop some structure and some systems that help these people develop skills that are going to be able to help them be more functional in life, we need to know about it and then we need to develop it because the burden to society is so huge if we don't.

Physicians acknowledged that they have a difficult time accessing services for patients in part because they neither know how to do so nor have the time to try to find out about FASD-focused services. One stated:

> Because I think physicians have enough on their plate. To then have to go and do that, you have a lot you have to do at each appointment. So I think that needs

to be a whole separate process to be done well and to be done thoroughly.

Fourteen of the physicians expressed the belief that the service information gap needed to be filled with a centralized network, system, or organization that served as a one-stop resource for easily accessible information about referrals, programs, and professionals specializing in FASD care throughout Alaska. One physician made the following statement: "It's hard to figure what's out there because it changes so much and [it] isn't visible anywhere. It's hard to figure out who to call or how to get people into it." An organization or person serving as a one-stop resource could not only support the physicians, but could also provide information directly to families and caregivers. Another physician expressed it this way:

> I think my resounding answer to everything is lack of a central person or services specific to fetal alcohol. And it is hard to build the mountain overnight but even if there was a resource person, someone who took an interest in it they don't even have to be medical, that was able to help physicians and families navigate options.

A subset of nine physicians spoke about the fact that adults who experience brain damage from prenatal alcohol exposure are a vulnerable group, likely to go undiagnosed and untreated. Physicians see these adults in their practice and struggle with the best way to address their medical needs and life issues: "I've certainly had adults that I thought were so scattered and in and out of the law that I was suspicious that was what was probably going on." They shared concerns about a complete lack of

FASD-related services across the full-continuum of care for this patient population affected by prenatal alcohol exposure, with one commenting: "What's really missing, absolutely not addressed at all, is adults with FAS and FASD and that is the stunning gap in our diagnosis and service system." Furthermore, physicians discussed a special population of adults that could greatly benefit from FASD diagnostic services and treatment, as well as support prevention efforts in Alaska:

> I see moms in clinic who I question because of the way that they interact with me about whether they might be affected. You see that they lose their children and then you kind of go "okay, so is this is a mother who's affected but nobody is really looking into that? What help does she need to be able to keep these children? How can we prevent her from having another child with an FASD?"

Just as services were perceived as nearly non-existent for adults, physicians had a sense of uncertainty and bleakness about the benefits of a diagnosis for this population. For children, a diagnosis was perceived as supporting the child and family by linking them to services at school or possibly qualifying for additional treatment and funding. For adults, the benefit of a diagnosis was perceived as less clear, especially since most individuals affected by prenatal exposure are not designated as mentally retarded:

> Because if you're not mentally retarded you can't get into assisted living, there's no services for you. So making a diagnosis would be very unsatisfying because then you go "here's your diagnosis. Good luck with the rest of your life, there's

> nothing we can do for you." So unless you're mentally retarded ...[in which case] you like throw a party, great, we're going to be able to get you into a supported living environment, we're going to be able to do all this stuff for you. But you have to be mentally retarded, which the vast majority is not.

Above all the services that were mentioned as necessary but unavailable for adults, one emerged in the interviews most frequently; specifically, physicians identified housing services for adults as a significant issue and unmet need, with one stating: "We need to build structured places for them to live and put them there. Otherwise they're just going to be taken advantage of in society. Our current society is just not going to work for them."

Providers and referral shortages. Eighteen of the physicians spoke of a shortage of key professionals who can provide FASD-related services and could be included on a comprehensive multidisciplinary referral list. Rising to the top of the list of needed referral resources were occupational therapists, speech and language pathologists, psychologists, psychiatrists, and public health nurses. One statement was:

> As I identify more and more of these kids, my speech and language therapists are all filled up. We now have waitlists of a year or two to get into speech therapy. We need more physical therapists or occupational therapists, we need more speech and language therapists, as well as more psychologists and psychiatrists that are interested and willing to take on these kids.

Physicians acknowledged that one of the most valuable services they can provide to an

individual who experiences an FASD is to serve as a medical home that coordinates referrals and facilitates access to specialty providers. However, without having access to knowledgeable professionals who can help provide comprehensive care, patients have poorer outcomes. This was illustrated by the following physician's statement:

> Assistance with the specialist that might be able to say that this kid does have FASD and there's anxiety and some depression and some ADHD and learning disabilities involving this, this, and this and this. Somebody that has that expertise to basically lay out what's there and what needs to be done in a way that we just don't have the time or the depth of experience in primary care to always do that.

Training and education gaps. In general, all but five physicians reported receiving little to no training during medical school and residency about FASD prevention, screening, diagnosis, and treatment. One summarized: "I don't feel that I know that much about it and it is a frustrating topic." Exceptions were those who sought out specialized training in FASD-related practice or were taught by faculty with expertise in the field. As noted by one physician,

> I only got a little by accident and that was because I had done an elective rotation. I elected to do some pediatrics up here at the Native hospital and it was only by accident as part of that. I had zero exposure to it through standard training.

Physicians who did receive at least some education during medical school and residency

did not perceive it as sufficient to result in comfort with providing FASD-related services. One stated:

> We were sensitized to it from my first year of medical school -- just what kind of syndrome it was. So in other words we learned about how to identify it. Some of these subtle things about how to manage it and stuff did not come up in my training. I don't think they necessarily ignored it, it was just that we didn't have a good physician based solution for it.

For physicians, lack of training and education during medical school and residency was concerning. They noted that as medical science advances, physicians have to update their knowledge related to the consequences of alcohol-exposed pregnancies. For example, one respondent commented about misconceptions that exist today:

> There is still a good chunk around who were taught differently in med school. [We need to] say "yes, this was the way it was, but it's not that way anymore." Things change a lot in medicine… it wasn't that long ago that they used to tell people that a glass of red wine was good for your baby. We need to make sure that they know that is not what we know nowadays...[alcohol] is not safe during pregnancy or while breast feeding.

Beyond concerns about insufficient training, physicians noted the struggle of medical programs to cover all aspects of medicine given the time constraints of medical school and residency. Some medical specialty programs have strict, universal

requirements and guidelines about content that needs to be covered during training. Particular domains are required for certification in many subspecialties; FASD education does not appear to be one of them. In specifically discussing family practice programs, one physician explained:

> The thing about family medicine is that it's very dogmatic about what you include in all of your training. Whereas in a lot of the other areas, it's left up to the program. And they may value it and decide that it's really important, and many programs do, but it's not dictated from a certification point of view.

Program certification requirements appeared to play a role in the level of FASD education and training available to medical students and residents.

The challenge of covering a vast amount of medical information in a short amount of time does not only affect FASD-related education. This issue was described as a broader concern not exclusive to FASD:

> The average medical student only gets two hours of this or that in medical school. Well, there are a lot of diseases and two hours on any given disease is a whole lot of time in medical school. We only spend about eight hours on heart disease and half of us are going to die of that.

This same concern was echoed by this physician:

> This reminds me a little bit of the conversation people often times have with me about the whole topic of nutrition in medical school and the common line for doctors to say, "I think we spend 15 minutes on the fourth day of the third week

> talking about nutrition." And obviously nutrition is a hugely important topic, and probably FAS is kind of like that - a hugely important topic that gets little attention. So finding ways to increase its visibility in medical school would obviously be a hugely important thing.

From a practical perspective, four physicians noted that not all providers need extensive training on the prevention and treatment of FASDs:

> I think it would be useless to do it during medical school because I don't think it is going to be pertinent to a lot of people coming out of medical school depending on what they are going to go into. But I do think it should be something that is better addressed during a pediatric residency. I think it could be done better but I don't know how.

Nevertheless, all physicians acknowledged that exposure to the basics, such as prevention of alcohol-exposed pregnancies and screening for FASDs was important, sufficient, and realistic during medical school or residency training. One physician articulated this concept in the following manner: "You read about it, you hear about it, and you may see a little bit of it. But until you actually have patients who suffer from the disorder, then really your experience is minimal."

Over half of the physicians discussed the importance of having opportunities to learn about FASD practices through continuing education. Access to educational opportunities through various media, tailored to often hectic schedules, was valued and identified as a possible avenue to create changes in practice behaviors:

> The primary way that physicians change their practices is through continuing education. But it has to be worth their time to spend on a specific topic. Whether it is online continuing education or going to a seminar or a convention, all of us have to keep up on our continuing medical education credits. I change some of the things that I do in my practice because I've learned it through continuing education.

Twenty of the 24 physicians expressed interest in gaining more knowledge about FASD practices; however, they were uncertain about how to access needed training, such as brief intervention strategies for prevention of alcohol-exposed pregnancies, FASD screening and diagnostic procedures, and effective treatment interventions for family members and caregivers. In addition, physicians noted that any training needs to be concise, practical, and delivered in an easily accessible manner. For example, one physician provided the following suggestion for getting basic information to physicians about preventing alcohol exposed pregnancies:

> You know a must read, a quick synopsis, "don't drink because it's one of the few known teratogens." There are just very simple, powerful phrases you could hand to physicians who may be kind of gray about how to deliver this message to patients.

Gaps in rural Alaska communities. Sixteen of the physicians with rural experience spoke about the inherent overall challenges of providing medical care in rural communities. One stated:

> Service gaps are the everyday experience of rural medicine and to some extent that's what I came out here for. I wanted to practice on a really broad spectrum, I wanted to do a little bit of everything, and I wanted to work in a community where I would have an impact. I have definitely done that, but you also discover that you're not very good at everything.

Rural physician respondents stated that they have to "put out fires all day long" and take care of the emergencies first. As one physician commented, "When you're stretched thin, handling the emergencies is what you do because you have to. FASD is never an emergency."

Physicians asserted that the nature of Alaska's size and geography will not change and that it contributes to the challenges in providing adequate FASD-related care. A commonly mentioned example was the difficulty in hiring and maintaining medical staff in rural communities:

> I think the biggest barrier is professionals. I've been here a [few] years and there's only one physician at the hospital who's been here longer than I have, and several, several, several who've come and gone through my tenure here. Now, I'm leaving.

In addition to noting shortages of medical doctors, over half of the physicians shared that they have no access to psychologists, speech and language pathologists, and occupational therapists in rural communities: "We need people to do all the roles. And the other thing is because the turnover is so high, everyone is chronically understaffed."

Physicians noted that when they do gain access to short-term itinerant professionals, these professionals generally have no specialty training in FASD prevention, diagnosis, and treatment.

Although similar gaps were noted in urban communities, rural communities were identified as having substantially larger difficulties related to the non-existence of programs, rather than simply difficulty in accessing existing services. Physicians working in rural communities shared that there was no infrastructure to support a fully functioning healthcare system, including physical, psychological, and social services. Therefore, they often had no specialty resources, programs, or providers within the community to whom to refer patients for FASD prevention, diagnosis, and treatment. One stated:

> We have to make the right referral, but we also have to have the infrastructure to make the right referral. I think what's lacking are different social programs, including neuropsychologists and behavioralists who can work with kids with special needs.

Due to lack of available services and providers in rural communities, rural physicians reported hesitation in diagnosing or identifying FASD issues when no programs and treatment options were available to address the problem once identified. For example, one physician shared the following sentiment:

> If they're going to ask a question and they're going to get a "yes" response on it, then they need to also be able to know what the system or their resources will

> allow them to do with it. So if you live in a little village and you ask somebody a question about alcohol use, and they say "yes" and you don't have anything to offer them. I think that sometimes that's a barrier. [It means] that "well, we're not going to ask that question because we don't know what to do with it if they answer 'yes.'"

Physicians highlighted concern for family members and caregivers of individuals experiencing FASDs. They reported that in smaller communities parents were not able to access the care and support they needed for their families and were required to travel to and navigate a larger system in urban Alaska to receive necessary services. In addition to the difficulties involved in raising a child experiencing a disability, not having services available to meet a child's needs was identified by physicians as a significant obstacle and source of stress for families:

> In order to know what you need, you have to be the expert on it. So I think it's harder. Especially, if they're in a small village, there's certainly not going to be the resources for that kid. So the parents would have to be way on top of it and be traveling to Anchorage for those things or you know what… they don't get it.

These systemic problems place the burden of assuring continuity of care on family members and caregivers.

Although physicians spoke about gaps in rural healthcare, they also mentioned important factors that have improved the lives of individuals with FASDs residing in rural communities. One such facilitator related to the perception that relatively stronger

bonds between rural medical providers and patients improved outcomes: "Just being in a small town...knowing your community, knowing your patients, having long-term relationships, helps to better support your patients with FASD." Another positive aspect of rural care related to the development of resiliency and strength among families and caregivers of individuals with FASDs. One respondent framed it this way:

> Parents really have to be advocates because the services aren't obvious, even more so than in the larger community... it's the Alaska way. You have to be more do-it-yourself oriented. I think it's the same thing for parents with children with fetal alcohol spectrum disorder because they have to be the experts. They have to become their do-it-yourself person.

Other Factors Influencing FASD Prevention and Care

Physicians discussed various non-medical factors they deemed influential on their practice and the broader field of FASDs. Figure 10 offers a visual representation of qualitative themes that emerged in the broad category entitled *Other Factors Influencing FASD Prevention and Care.* The following section provides a detailed summary of results inherent in each theme contained within this category. The themes include *Public Awareness, Community Norms and Responsibilities, Misconceptions about FASD, and Stigma related to Prenatal Alcohol Exposure and FASDs.*

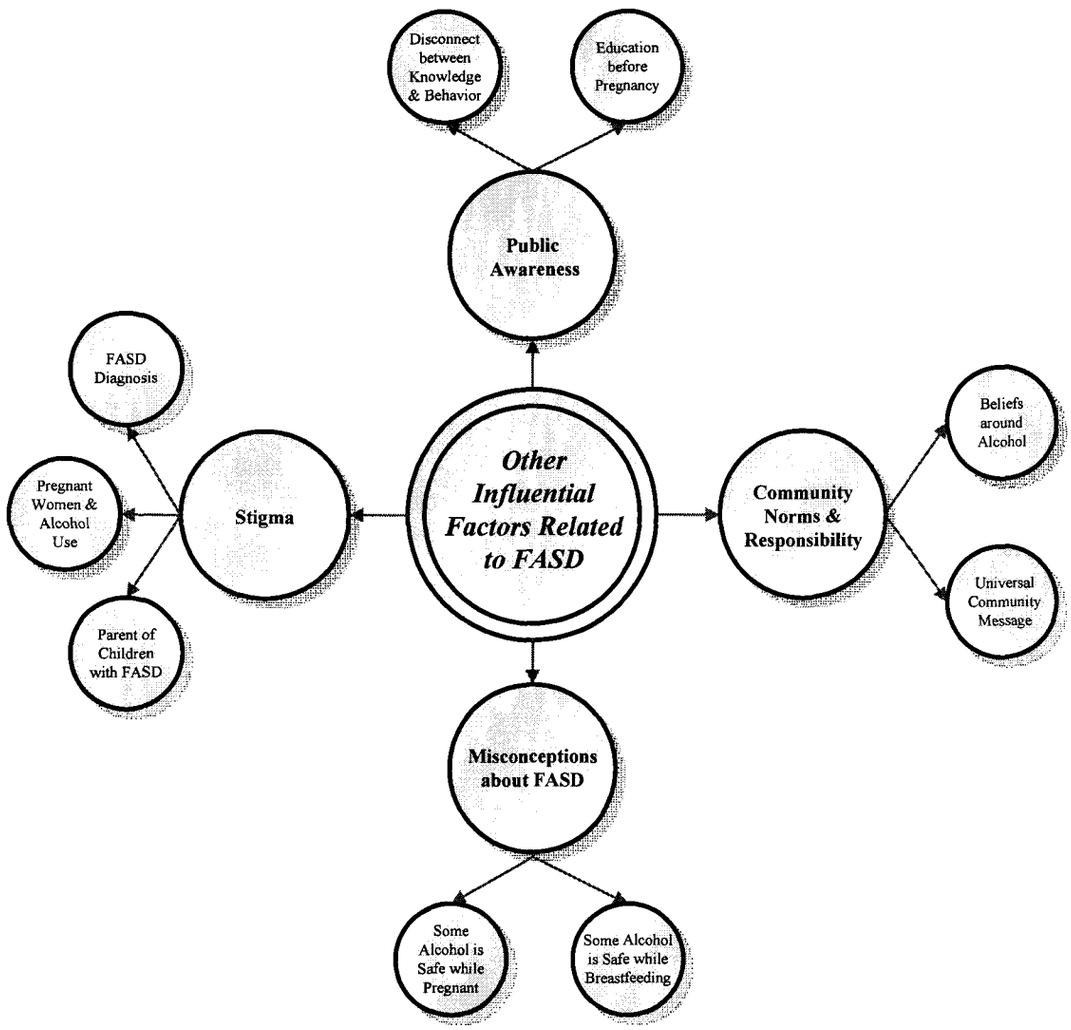


Figure 10. Other Factors Influencing FASD Prevention and Care

Public awareness. Physicians reported that strong public awareness around health issues can support prevention and treatment work with patients. Around the topic of FASDs, physicians shared an appreciation for the impressive public education campaign that has addressed FAS in Alaska. One commented: "I think all in all we've done a very good job of getting out into the culture that pregnant women shouldn't

drink alcohol." However, nine of the physicians expressed concern about a disconnect between public health messages and their own communication with patients regarding personal health behaviors:

> I'm still amazed at how it hasn't filtered down. Much like condom use... where people still tend to ignore this pretty bona fide healthcare [issue]. Health behaviors can result in maximizing the prevention of disease. There's still a disconnect around this.

Physicians discussed that it takes time for public health campaigns to result in health behavior change and highlighted the successes of anti-smoking campaigns over the past two decades. Physicians suggested FASD prevention campaigns could be informed by approaches to effect the prevention of cigarette smoking:

> I use the example of smoking because if somebody had asked me in the 1980's whether the tobacco company legislation and all the prohibitions against smoking would have been where we are now, I would have said, "No way." I think that's maybe where we are now with social attitudes about unsafe drinking during pregnancy and how to help the public to become much more aware of this. I think we just have to keep working at it.

Physicians further noted that effectiveness of public awareness endeavors was influenced by the fact that approximately half of all pregnancies are unplanned, implying that many women use alcohol prior to knowing they were pregnant. Physicians suggested that FASD prevention messages needed to reach individuals at an

early age, requiring efforts that move beyond public health campaigns into the realm of early education. This important point was made in the following manner:

> I really see a role of having some sort of mandatory health education having to do with high school when they're concrete and their abstract thinking is starting to evolve. These kids aren't getting exposed yet to the actual message. When they're becoming early adults, [they need] to learn about FAS in particular. And it's not a requirement.

Community norms and responsibilities. Physicians discussed the impact of community norms surrounding alcohol use, as well as communities' responsibility to address health and social issues (such as alcohol use and abuse) locally. Over half of the physicians shared that although they understood the involvement of physicians in FASD prevention and treatment, they did not support sole reliance on medical practitioners to address this larger social issue. This belief was elucidated by one physician in the following statement:

> I don't want to undermine or de-emphasize the role and importance of physicians but from my view, you really need to be team players and there's nothing holy and all that special about physicians in this particular disease. The big deal for me is to have the community orchestrated around these issues from a prevention [perspective].

From physicians' viewpoints, community norms about alcohol use during pregnancy are complicated by the fact that alcohol distribution and consumption is legal

in many communities in Alaska. Attempts to restrict only select community members from access to a legal substance were perceived as problematic. Physicians were unsure about how to support and work with communities in addressing this dilemma. One commented:

> I think a lot of the communities need to take more responsibility for prevention of FAS. We have some of the villages here that make money by running a liquor store. I think that's appalling because they are doing the community a disservice. I think maybe, on a community level, taking a little bit more of an initiative on FASD prevention or the appropriate use of alcohol. It's a gap or a place where work could be done. Not just making it something that's an issue for the healthcare providers, but making it an issue for the whole community.

Related to the notion of community responsibility, physicians believed that messages about alcohol consumption by women of child-bearing age needed to emerge from all community members, including families, neighbors, school personnel and programs, and health and social services organizations: "It's a social problem that basically requires all of us and the most effective way to do it is to truly focus on prevention." By engaging all community structures, physicians expressed the hope that prevention messages would have more impact on rates of alcohol exposed pregnancies in Alaska. One statement was:

> The community has to get organized around it and people need to tell if they have their friends that are drinking and say "you shouldn't be drinking if you're

pregnant. Why are you drinking?" Now that being said, just telling an addicted person to stop doesn't work and that's one of the big issues for the intervention.

Misconceptions about prenatal alcohol exposure. Although physicians praised public awareness efforts around FASD prevention, they recounted many misconceptions in their professional work with patients and colleagues. They reported encounters with women who were unaware of the dangers of alcohol consumption during pregnancy and breastfeeding. They were concerned that this misinformation came from incorrect messages from other health or allied healthcare providers who lack education or who have misinformation about alcohol's danger during pregnancy and breastfeeding. One stated:

> I think that there is more awareness now about the risk even of a little bit of alcohol, but there are still some old myths around that it's okay to drink a little bit in pregnancy. And breast feeding for that matter.

Physicians expressed the belief that professional colleagues do not educate patients about the fact that the only known safe amount of alcohol during pregnancy is no alcohol. Of particular concern were prevention practices of OB/GYNS, as evidenced in the following comment:

> [OB/GYNs] are not testing for alcohol, they're just testing for drugs, and a lot of OBs consider alcohol to be a legal, okay thing. They tell the mom, "Go ahead and have a beer to relax, or when you're anxious." And twenty years ago we used to tell moms to go ahead and have a beer to bring in their breast milk. We

now know that's not good and hopefully we're not doing that anymore.

Stigma related to prenatal alcohol exposure and FASDs. Although physicians shared discomfort with the notion that stigma might affect professional practices, over half acknowledged that stigmatization is a reality. They identified the following three ways in which stigma interferes with successful prevention and treatment approaches: stigma related to negative views of women who consume alcohol during pregnancy; stigma placed on parents of children diagnosed with FASDs; and stigma related to being labeled as an individual who experiences an FASD.

Physicians surmised that negative perceptions of women who consume alcohol during pregnancy have far-reaching consequences on prevention efforts. Examples of women's reluctance to disclose alcohol use included women not honestly reporting prenatal alcohol use due to fear of being judged, women not seeking treatment due to feelings of shame or embarrassment, and women avoiding certain medical providers or avoiding medical care altogether (either of which may lead to poor prenatal care). One physician stated:

> I think there is a strong condemnation of women who drink while they're pregnant. Most of us have very strong feelings about children and doing something that hurts children. I don't want to say it ought to be stigmatized because again I do accept the disease model of alcoholism. And I have seen judgmental attitudes about women whose children have been born with FASD on the part of professionals and non-professionals.

Six physicians shared that although they were concerned about the ramifications of stigma surrounding FASDs, they were not immune to these same feelings and experiences, with one responding:

> I think all of us have some preconceived ideas about people who drink to excess and don't have the same values in terms of having a healthy pregnancy that we do. And so there is stigma there and sometimes it is very hard to relate to these people.

They expressed the need to put any judgmental feelings aside and address the needs of their patients regardless. For example, one physician stated:

> I always try to treat the child; do what's best for the child. Sometimes you feel a little frustrated or angry that a parent could do things that would put the child at risk and you have to separate your emotions from what's best for the patient.

Three physicians discussed an alternative perspective on the effects of stigma associated with alcohol consumption during pregnancy. This subgroup of respondents identified an upside to stigma by seeing it as a means to deter women from consuming alcohol during pregnancy:

> If women are taught that no alcohol is okay during pregnancy and people give them a hard time, like say if you saw a pregnant woman at a bar drinking. I think there is a social stigma about it and I think in some ways that can be helpful as long as it's supportive. If you have somebody who has a history of drinking and is now pregnant, if she has people around her who can help educate

> her about how alcohol can be problematic for a fetus and for a woman, and then help her. Help her access resources to avoid alcohol, get into treatment programs, things like that. I think sometimes a stigma can result in support, education, and help. But if it becomes too negative, I think it might even backfire.

In addition to effects of stigma on FASD prevention, physicians mentioned that stigma, as well as shame, continued to have a negative influence on care following the birth of a child. This barrier was mainly related to concern that women and family members may not report alcohol exposure in utero. Without this important information, physicians have difficulty providing effective and appropriate treatment for an affected child, opening the door for misdiagnosis or non-diagnosis. One stated:

> There are a number of mothers who ardently deny that their child has alcohol because they didn't drink that much when they were pregnant...and I think that they might be less liable to seek medical care for their children if each time they come to the care, they're reminded, "you did this because you were drinking when you where pregnant." I don't think anyone is saying that FASD isn't worth treating or FASD is a disease that we just let go. But I could see some reluctance to seek treatment when each episode of care was a not so subtle reminder that you had caused this disease by doing something.

Equally important to stigma placed upon women who drink alcohol during pregnancy is stigma placed upon individuals "labeled" or diagnosed with FASDs.

Physicians were aware of the benefits of early diagnosis, recognizing it as a protective factor that improves long-term outcomes. Nevertheless, they discussed concerns about professionals' and non-professionals' perceptions of individuals experiencing FASDs. This concept was illustrated in this physician's statement:

> Unfortunately, the values in our society tend to look down on the vulnerable and the weak. It's very easy to be hypocritical and self-righteous and some of this comes, and I'm reflecting on my own upbringing, a lot of ideas that drinking is evil and immoral and if a child is the result of this, unfortunately they often will carry the blame.

Physicians discussed the belief that little can be done to support and treat a patient experiencing FASDs, indicating that "there is no sense of hope about providing some kind of quality life for these people." In general, respondents expressed the sense that people who experience FASDs are stigmatized by society and "hav[e] few options in life." This sentiment was further elucidated by one physician who stated:

> Certainly for fetal alcohol syndrome you just would be idiotic or very irrational to blame the child. But that's what happens with stigma because if you're frightened by it and you think they're hopeless, you don't do anything. That in essence is blaming the victim and so getting away from that is difficult.

Chapter 6 Discussion of Quantitative and Qualitative Findings

Integrating quantitative and qualitative methodologies allows for an increased depth and breadth of information to serve as a strong basis of evidence for drawing meaningful and valid conclusions from the study, conclusions that provide significant guidance for developing purposeful recommendations for improving FASD primary and secondary prevention practices by Alaskan physicians. Through the use of an explanatory mixed methods design, the overall purpose of study was to examine physicians' level of knowledge, attitudes, practices, and understanding related to FASD to identify effective ways to educate and train physicians about FASD primary and secondary prevention in Alaska. The following discussion integrates the findings from Phase One (quantitative) and Phase Two (qualitative) of the current study.

FASD Knowledge

Physicians who responded to the KABB survey were generally knowledgeable about alcohol being a teratogen and the risks of alcohol consumption during pregnancy and breastfeeding. However, a subset of providers considered an occasional alcoholic beverage to be acceptable during pregnancy and breastfeeding, identified a safe number of alcoholic drinks for consumption during pregnancy, and responded that drinking during the third trimester was probably safe. More specifically, approximately 24% of physicians identified a safe number of alcoholic drinks for consumption during pregnancy, with 4% of the physicians identifying *5 or more drinks* as an acceptable level of consumption. Given that *5 or more drinks* is an amount that exceeds the

common definition of a binge drinking episode, believing that such a level of alcohol consumption is acceptable for a pregnant woman is in direct contact with accepted medical guidelines. Indeed, this level of drinking is considered to be a high-risk alcohol consumption level for pregnant women and warrants intervention by the medical provider (Bertrand et al., 2004). Moreover, 62% of physicians sanctioned occasional use of alcohol by nursing mothers. Once again, this contradicts current medical recommendations (American Academy of Pediatrics, 2005). Based on these findings, some Alaskan physicians may be providing misinformation to their patients, increasing the risk of both prenatal and postnatal effects of alcohol.

With regard to the timing of alcohol consumption during pregnancy, current research suggests that no alcohol consumption during any stage of pregnancy is the safest option. However, the third trimester is by some researchers considered to be the potentially least damaging period for alcohol consumption as the fetus is more developed by this time (Rudeen, 2009). Conversely, the first trimester is considered to be the most potentially damaging trimester for alcohol consumption because it represents the most critical period of embryo and fetal development (Rudeen, 2009). Although most physicians responded correctly that no trimester during pregnancy was safe for alcohol use, approximately 13% noted that the third trimester was safe for alcohol consumption. Even though it is not considered "safe" to consume alcohol during any trimester, this finding suggests that some physicians were aware of the severity of prenatal effects across gestation. On the other hand, 2% of physicians

identified the first trimester as the safest time period to consume alcohol during pregnancy, suggesting a dangerous, albeit small, gap in knowledge.

Concerns regarding lack of knowledge on the part of physicians and patients emerged as a theme in the qualitative interviews as well. Physicians shared that they encounter women who are unaware of the dangers of alcohol consumption during pregnancy and breastfeeding. Some physicians asserted that this misinformation comes either from incorrect messages delivered by healthcare providers or lack of patient education about the dangers of alcohol use during pregnancy and breastfeeding. Physicians reported that some of their professional colleagues do not educate their patients about research that suggests no alcohol during pregnancy is the only known safe amount of alcohol.

It is interesting to note that rural physicians exhibited a higher level of knowledge regarding risk of alcohol consumption during pregnancy than did their urban counterparts. Rural physicians were more likely than urban physicians to report that alcohol consumption is not appropriate during pregnancy, identify zero drinks during pregnancy as the safest amount of alcohol, and to acknowledge that no trimester during pregnancy was safe for alcohol consumption. This finding may be reflective of better physician knowledge gained through practice experience in rural Alaska communities that have higher rates of alcohol abuse and FASDs. Also, rural physicians were less likely to have access to an FASD expert to whom to refer patients; therefore, they may have had no choice but to educate themselves on these issues. Further, pediatricians

were more likely than other specialists to identify zero drinks during pregnancy as the safest amount of alcohol consumption. Similar to past research, pediatricians appeared to be more aware of the effects of alcohol and more comfortable with addressing FASDs in their practice (Nanson et al., 1995). Perhaps pediatricians more than other physician specialties are faced with the outcomes of drinking during pregnancy.

FASD Prevention

By and large, physicians acknowledged their role in FASD prevention with their patients, including responsibilities for screening for alcohol use by female patients (women of childbearing age and pregnant women); educating and counseling women about the consequences of consuming alcohol during pregnancy; and referring women to substance abuse treatment services as needed. Physicians noted the importance of practicing universal screening by means of verbal questioning or self-report alcohol screening tools. This finding is aligned with current medical practice recommendations that physicians need to conduct universal alcohol use screenings with all women of childbearing age, utilizing standardized tools (such as the CAGE, T-ACE, or TWEAK; O'Connor, Floyd, & Guiton, 2009).

Regardless of screening method, physicians shared that it was very important to consider patient-provider relationships when assessing alcohol use in general and counseling patients about alcohol use during pregnancy. Key components identified as making the relationship more likely to be effective included sensitivity, trust, and non-judgment. This perspective fits with current promising practices in preventing prenatal

alcohol exposures. For example, over the past decade, studies have reported positive results using brief motivational interventions for FASD prevention (Floyd et al., 2007; Handmaker & Wilbourne, 2001; Project CHOICES Research Group, 2002). Brief motivational interventions emphasize the importance of respecting patient autonomy and utilizing a non-judgmental approach.

Although acknowledging the importance of prevention efforts, physicians identified several barriers that impede their ability to provide prevention services. These barriers included the underreporting of alcohol use by women of childbearing age and pregnant women; lack of time and reimbursement for providing comprehensive primary prevention services; low level of comfort and self-efficacy around preventing alcohol-exposed pregnancies; lack of prenatal visits, reducing the number of opportunities for prevention interventions; and the manner in which alcohol dependence is viewed within the medical profession (i.e., moral model vs. disease model). Although acknowledging the importance of screenings, physicians were less than confident that they occurred in all settings by all providers because of time constraints on physician visits and skill levels of physicians. Most expressed the belief that OB/GYNs and family practice physicians were best positioned to conduct screenings and interventions. Yet, pediatricians reported feeling significantly more confident in their skills than OB/GYNs. Physicians reported that the current healthcare system is part of the problem with inadequate FASD-related care because it does not routinely reimburse and support the integration of behavioral health professionals into routine

practice. The desire for an integration of behavioral health and primary care is not limited to FASD-related care. It is consistent with an increasingly powerful movement within healthcare systems to develop person-centered healthcare homes with integrated behavioral health and primary medical care services (Mauer, 2009).

Compounding these challenges, physicians identified gaps in services, systems, and training that affect their ability to address FASD prevention in their practice. For example, physicians reported difficulties in referring patients to substance abuse treatment due to insufficient services in Alaska, including alcohol detoxification and inpatient and outpatient treatment options. Rural physicians have even more dire perspectives, noting that services are not merely limited but missing altogether. Physicians discussed the overwhelming challenges in addressing alcohol abuse issues with no access to professionals who provide substance abuse treatment, and the ethical dilemma of identifying alcohol use when no treatment supports can be offered. Shortages of treatment services and medical and behavioral health professionals are not unique to Alaska and have long been documented in research identifying challenges in addressing rural-urban healthcare disparities (Johnson, Brems, Warner, & Roberts, 2006; Tough, Ediger, Hicks, & Clarke, 2008). This concern is also recognized by the State of Alaska as illustrated in the Healthy Alaskans 2010 emphasis on increasing support for preventive services and access to care as a means to improve maternal, infant, and child health (Alaska Department of Health and Social Services, 2001).

FASD Screening and Diagnosis

Physicians acknowledged their role in screening for FASDs within their patient population and facilitating the diagnostic process for patients suspected of having brain damage due to prenatal alcohol exposure. With regard to FASD screening and recognition, pediatricians and family practice physicians appeared to have opportunities for early identification of FASDs in children through neonatal assessments and periodic well-child examinations. Their ability to screen for FASDs and refer for diagnostic assessments at an early age was viewed as a means for improving long-term outcomes for patients. Willingness to screen for FASDs suggests a proactive perspective as it is consistent with research evidence that diagnosis before age six reduces the likelihood of secondary disabilities for individuals who experience FAS (Streissguth et al., 1996).

Although they recognized their role and opportunity to screen for FASDs, physicians acknowledged difficulties screening children who do not possess the growth deficiencies and facial characteristics of FAS. In such cases, diagnosis is more related to functional deficits (e.g., cognitive, executive functioning, motor functioning, social skills, and attention). Physicians found it challenging to decide whether a diagnostic assessment was warranted, especially if they were unable to confirm prenatal alcohol exposure. Lack of a standardized system for documenting prenatal alcohol exposure in charts of newborns was viewed as a barrier to both screening and diagnosis.

Physicians' perspectives on their medical responsibilities related to conducting FASD diagnoses varied. Physicians viewed their role as providers who could facilitate

the process of securing a diagnostic assessment, rather than serving as diagnosticians. Developing a specialty in FASD diagnosis was reported as outside of the focus of medical school and residency training. Physicians felt strongly that only providers with expertise in the FASD diagnostic process should render diagnostic services. These perceptions gathered through the qualitative interviewees were confirmed by results of the KABB survey. Specifically, KABB findings suggested that physicians as a whole have low levels of comfort with their ability to conduct FASD diagnoses, as compared to other FASD-related practices.

Physicians expressed more confidence in being able to render FASD diagnoses in cases for which prenatal alcohol exposure was documented in the medical record and growth deficiencies and facial dysmorphology were present. Yet even in these clearer and more straightforward cases, physicians preferred getting a second opinion to confirm the accuracy of their diagnosis. Most commonly, physicians discussed referring patients to pediatricians with FASD expertise or to FASD diagnostic teams. However, according to the KABB survey, pediatricians did not report significantly higher levels of comfort with diagnosing FASDs than did family practice physicians. Therefore, it was unlikely that they considered themselves to have expertise beyond that of family practice physicians and it was unclear how pediatricians might handle FASD diagnostic referrals. Another exception to referring to a non-expert to diagnose FASDs occurred among providers practicing in rural communities with limited availability or access to specialized medical services. In such situations, family practice physicians

were identified as being the most logical providers to render a diagnosis, which may explain why family practice physicians rated their comfort and skill significantly higher than OB/GYNs.

With regard to barriers, physicians discussed their inability to access diagnostic services for patients once they were screened for FASDs and identified as being in need of further evaluations by FASD diagnostic specialists. Although most physicians were aware of the existence of FASD multidisciplinary diagnostic teams within Alaska, many reported difficulty referring patients for a diagnosis due to the absence of a team in their community, uncertainty about referral procedures and criteria, and concerns about waitlists and low diagnostic capacity. This finding, based on the KABB survey, was supported by the interviews as well, with 40% of physicians reporting no access to FASD screening or diagnostic services.

Additionally, physicians shared that a significant barrier to FASD screening and diagnosis was effective communication with and engagement of parents and caregivers in the diagnostic process. Communication with caregivers was considered essential to screening and diagnosis. Yet, physicians revealed that they had not received training about how to support caregivers around this emotional subject that often raised feelings of guilt, sadness, and loss. If dealt with in an insensitive manner, the physician-parent consultation was feared to result in avoidance of the issue and lack of follow-through with ongoing care.

Long-term Medical Care for FASDs

Regarding their role in ensuring long-term medical care for individuals experiencing FASDs, physicians reported that treating FASDs required considerable amounts of physician time and included intensive care coordination efforts to achieve adequate ongoing care. In this context, physicians discussed the possibilities and challenges of using newer medical practice methodologies, such as group visits and service as a medical home. Development of medical homes and the stress on care coordination are in alignment with the American Academy of Pediatrics (AAP) Call to Action, appealing to physicians to address individuals with FASDs as having complex disabilities that require comprehensive treatment efforts with a centralized location for coordination (AAP, 2007). Physicians identified pediatricians and family practice physicians as the logical providers to offer this form of care. Corroborating these interview findings, data from the KABB survey showed that pediatricians rated their level of comfort and skill with FASD primary and secondary prevention as significantly higher than OB/GYNs. Although no research is available to understand better this finding, it may be attributable to pediatricians having more specialized training in providing care to children with brain-based physical disabilities and greater exposure to patients experiencing FASDs.

Physicians identified several barriers and gaps that impeded their ability to provide comprehensive ongoing care for FASDs. In particular, physicians neither have time to provide nor to research referral targets for FASD-focused services. This

qualitative finding was corroborated by KABB survey results, which indicated that approximately 30% of physicians reported no awareness of local FASD resources and approximately 40% reported no access to FASD screening or diagnostic services. Pediatricians reported a significantly higher level of awareness of and access to services than family physicians or OB/GYNs.

Physicians reported that they would benefit from a centralized network, system, or organization that serves as a one-stop resource for easily accessible information about referrals, programs, and professionals specializing in FASD care throughout Alaska. Shortages of key professionals (i.e., occupational therapists, speech and language pathologists, psychologists, psychiatrists, and public health nurses) were viewed as hindrances to physicians' ability to connect patients with the care necessary to increase the likelihood of positive long-term outcomes. Once again, the medical home model was viewed as a possible solution. In addition to challenges related to providing ongoing care for children and their families, physicians addressed frustration over nearly non-existent support services for adults who are affected by FASDs. Frustration with the lack of availability of treatment supports has led them not to pursue FASD screening, diagnosis, or any other form of specialized treatment with their adult patients.

Conclusions

Due to the comprehensive range of healthcare services provided by physicians, they are in a unique position to influence multiple aspects of FASD-related care,

spanning from primary prevention to long-term medical care. Physicians in this study, namely pediatricians, family practice physicians, and OB/GYNs, possessed a solid knowledge base about FASDs and alcohol use during pregnancy and seemed acutely aware of their own important roles in FASD-related practices. However, knowledge and skill deficits remain that, if addressed, could enhance Alaskan efforts to reduce FASD prevalence rates, prevent development of secondary disabilities due to FASD misdiagnosis or non-diagnosis, and improve long-term outcomes through effectively coordinated multidisciplinary care across the lifespan.

For physicians to reach their full potential in contributing to primary and secondary prevention of FASD, several entities (i.e., medical schools, residency programs, and developers of education and training materials for physicians and other providers) need to acknowledge and help address the challenges and obstacles outlined by physicians. Through participation in this study, Alaskan physicians have identified systemic and professional barriers that affect FASD-related practice, educational and training needs related to their ability to conduct primary and secondary prevention, and service gaps and access challenges that impede their FASD-related services. The next chapter will use this background information to develop a set of recommendations for an FASD Education and Practice Improvement Plan.

Limitations

The current study contains a number of limitations that must be considered when interpreting findings and recommendations. With regard to Phase One, although the

overall response rate on the KABB survey was consistent with normative rates for physicians (Cummings, Savitz, & Konrad, 2001), response rates varied depending on medical specialty (pediatricians, 60%; OB/GYNs, 49%; family physicians, 48%). As pediatricians obtained the highest response rate, it is possible that they had greater interest in FASDs and were more likely to complete the survey. In addition, the KABB survey simply assessed self-reported attitudes and behaviors that may have been confounded by social desirability biases.

To counterbalance the overrepresentation of pediatricians in the survey sample, efforts were made in the qualitative phase to recruit an equal number of physicians across medical specialties, geographic practice regions, and levels of expertise. However, given the time commitment of the interview and challenging schedules of physicians, physicians who were more interested in and knowledgeable about the topic of FASDs were more likely to complete the interview, resulting in possibly biased opinions of respondents who had a higher level of FASD awareness than the general physician population.

In addition, due to the shortage of OB/GYNs in rural Alaska, family physicians who were actively practicing obstetrics had to be substituted for rural OB/GYNs. Over 80% of physicians, regardless of current place of residence, reported having practiced medicine in both rural and urban Alaska. These realities may limit the conclusions that can be drawn about differences across medical specialties and geographic regions. Given these methodological issues, care needs to be taken about generalizing or

transferring the gathered information to specific specialists and geographic locations.

Relatedly, caution is necessary about extrapolating from these data to geographic regions outside of the state of Alaska. The study sample only represents professionals in Alaska, a state with high FASD rates and a history of considerable statewide FASD education and prevention efforts (Information Insights, 2005). FASD awareness and medical practices may differ across the US, as does incidence of the disorder.

Chapter 7 FASD Education and Practice Improvement Plan

Phase Three of this study combined information from Phases One and Two with a literature review in order to develop a plan for effective awareness-raising and education efforts to increase knowledge, enhance attitudes, correct beliefs, and change behaviors of physicians as related to FASD primary and secondary prevention, diagnosis, and treatment. In addition to addressing the research questions examined in this study, findings are incorporated into four Phase Three products, namely, 1) an in-depth summary of barriers related to FASD practices, FASD prevention, systems challenges, service barriers, and training gaps identified by Alaskan physicians; 2) recommendations for possible healthcare system changes that would better support primary and secondary prevention practices by physicians; 3) recommendations outlining strategies for improving physicians' FASD-related practices; and 4) curriculum recommendations related to educational and training needs of Alaskan physicians.

Summary of Practice-related Barriers

To understand the education, training, and practice needs of physicians with regard to FASDs, it is important to review their perceptions of systemic and professional barriers, especially as related to obstacles to FASD prevention, alcohol use screening, diagnosis, and intervention. Based on the findings for Phases One and Two, Tables 17 through 19 provide an overview of physician-identified challenges and their effects on practice, as well as the health of the women and children whom they serve.

Table 17

Summary of Barriers to FASD Prevention

Barrier	*Effect on Practice*	*Effect on Patients and Caregivers*
Poor self-report of alcohol use by women of childbearing age and pregnant women	Decreases opportunities for primary prevention to reduce alcohol-exposed pregnancies	Fails to address reduction of alcohol use during pregnancy
Limited opportunities to reach women at risk for an alcohol-exposed pregnancy due to poor participation in recommended medical care (i.e., annual examinations)	Decreases opportunities to address the unsafe combination of alcohol consumption, sexual activity, and ineffective use of contraceptives	Reduces the opportunity for women to become educated about the dangers of prenatal alcohol exposure
Inadequate prenatal care	Decreases physicians' access to pregnant women early in gestation, which is a critical time for damage from alcohol exposure	Increases the likelihood that women will drink during pregnancy and children will be born prenatally exposed to alcohol
Inadequate postnatal care	Decreases physicians' access to women and newborns at a time when it is important to educate about the dangers of alcohol consumption during breastfeeding	Increases the likelihood that women will drink while breastfeeding and infants will be postnatally exposed to alcohol
Lack of comfort and self-efficacy around discussing alcohol use and abuse issues	Decreases physicians' knowledge about the health practices of their patients	Leads to lost opportunities to educate women about the dangers of alcohol consumption
Lack of time and reimbursement to adequately provide FASD primary prevention activities	Decrease in primary prevention activities that may lead to more serious long-term health issues, such as FASDs	Reduces the opportunity to education women about the consequences of alcohol consumption during pregnancy
View of alcohol dependence as a moral impairment or personal choice	Decreases physicians' ability to build non-judgmental, open relationships with patients, which could lead to an honest conversation about alcohol use, its consequences for the fetus, and ways of obtaining support for maintaining sobriety during pregnancy	Reduces the self-report of alcohol use and increases the risk of alcohol-exposed pregnancies

Table 18

Summary of Barriers to FASD Screening and Diagnosis

Barrier	*Effect on Practice*	*Effect on Patients and Caregivers*
Lack of a standardized system for documenting prenatal alcohol exposure in the charts of newborns	Decreases the physicians' ability to confirm prenatal alcohol exposure and to assess the amount and timing of the alcohol exposure, thereby negatively affecting the diagnostic process	Reduces the likelihood of an accurate diagnosis and the benefits of an early diagnosis (i.e., access to early intervention services)
Lack of confidence physicians feel in their ability to render a diagnosis or make an appropriate referral for a diagnosis	Decreases appropriate referrals to diagnostic services and diagnostic assessment	Fails to provide accurate screening and diagnostic services, while increasing the possibility of misdiagnoses and development of secondary disabilities for the patient
Challenges in accurately screening for FASD when cognitive deficits are the primary clinical triggers	Decreases appropriate referrals to diagnostic services	Fails to provide accurate screening, while increasing the possibility of misdiagnoses and development of secondary disabilities for the patient
Lack of communication skills for engaging parents and caregivers regarding the need for FASD screening and diagnosis	Decreases physicians' effectiveness in supporting patients and caregivers and increases the anxiety-provoking nature of these difficult conversations for physicians	Fails to educate individuals and families about the importance of an early diagnosis and the benefits of increased protective factors

Table 19

Summary of Barriers to FASD Ongoing Medical Care and Treatment

Barrier	*Effect on Practice*	*Effect on Patients and Caregivers*
Lack of standardized treatment protocols for providing ongoing medical care to individuals experiencing FASDs	Decreases physicians' ability to identify and implement effective interventions, especially when determining treatment for functional deficits	Fails to address ongoing medical needs of individuals experiencing FASDs and their caregivers
Lack of time and resources to assure that individuals experiencing FASDs are receiving the full continuum of care needed for the best outcomes	Decreases physicians' ability to provide long-term effective FASD-related care	Reduces the likelihood that individuals with FASDs will receive needed referrals, secure these services, and have positive treatment outcomes.
Lack of understanding about how the functional deficits of FASDs manifest and affect adherence to medical care recommendations	Decreases physicians' ability to adapt their routine practices to better care for individuals experiencing FASDs	Increases the likelihood that patients and caregivers will fail to understand medical terminology and follow medical regimes and recommendations

Summary of FASD Service, System, and Training Gaps

In addition to acknowledging barriers related to FASD care, physicians identified gaps in services, systems, and training and education that affect their FASD-related medical practices. Based on findings for Phases One and Two, Table 20 provides an overview of physician-identified gaps and their effects on day-to-day practice, as well as the health of the women and children whom they serve.

Table 20

Summary of Service, System, and Training Gaps

Barrier	*Effect on Practice*	*Effect on Patients and Caregivers*
Insufficient substance abuse treatment services in Alaska, including alcohol detoxification and inpatient and outpatient treatment options	Decreases physicians' ability to support patients in abstaining and receiving substance abuse treatment	Fails to provided the needed support for women experiencing alcohol abuse and dependence issues
Inability to refer patients for a diagnosis due to difficulty locating an FASD diagnostic specialist or an FASD diagnostic team close to their community	Decrease in referrals for diagnostic services and increased frustration related to long waitlists and teams' low diagnostic capacity	Reduces the number of individuals able to access diagnostic services and receive FASD-related care
Limited resources and skills to address the recommendations provided in the diagnostic assessment reports	Decreases physicians' ability to adhere to treatment recommendations, as the service limitations of the home community are not taken into consideration	Fails to provide patients and caregivers with the support that is recommended for optimal care
Lack of a centralized network, system, or organization to serve as a one-stop resource for easily accessing information about referrals, programs, and professionals specializing in FASD care throughout Alaska	Decreases physicians' access to FASD-related services for their patients	Reduces the likelihood that patients will be referred for a diagnosis and provided care incorporating a multidisciplinary approach
Lack of FASD-specific resources for adults	Decreases physicians' willingness to refer adults for a diagnosis due to the development of a mixed viewpoint on whether seeking a diagnosis is useful for the patient, as it does not lead to increased access to services	Reduces the possibility of adult patients to qualify for treatment services and decreases the likelihood of positive treatment outcomes
Shortage of key professionals who provide FASD-related services	Decreases physicians' ability to coordinate referrals and facilitate access to specialty providers	Reduces the positive outcomes associated with multidisciplinary care at a young age
Lack of comprehensive care	Decreases physicians' ability to provide appropriate amount and type of care	Reduces the positive outcomes associated with multidisciplinary care and contributes to disjointed medical care
No access to FASD prevention, diagnosis, and treatment services in rural communities	Decreases physicians' treatment options for patients	Fails to provide specialized treatment proven to improve outcomes for patients and families
Lack of medical and allied health professionals in rural communities	Decreases physicians' referral options for patients	Requires travel outside of home community to get medical needs met, increasing expenses to patients and families or lack of specialized treatment
No system in place to support continuity of care in rural communities	Decreases physicians' ability to provide adequate care coordination, resulting in disjointed care	Fails to provide comprehensive care, resulting in poorer outcomes for patients and families
Insufficient FASD-related training and education in medical schools and residencies	Decreases physicians' comfort and competence in providing FASD-related services, such as brief intervention strategies for preventing alcohol-exposed pregnancies, FASD screening	Fails to acknowledge the role of physicians in preventing the number one ranked preventable birth defect in the US.
Lack of useful continuing medical education opportunities	Decreases physicians' ability to gain more in-depth practice knowledge around FASD care	Reduces the chances of patients and caregivers for receiving up-to-date diagnostic and treatment services related to FASD

FASD-related Service and System Improvement Recommendations

Findings from Phases One and Two clarified that many of the challenges and obstacles experienced by physicians are beyond their control and need to be addressed not only as independent practice issues but as larger public health, workforce

development, and healthcare systems issues. To acknowledge and address these obstacles, a set of systems improvement recommendations are offered here to support and augment the recommendations for physicians. Implementation of systems changes represents a crucial foundation upon which to implement the physician practice and training recommendations. In fact, the very success of physician-related suggestions may hinge on the availability of the systems and structures offered in the public health, workforce development, and health systems change recommendations. Interventions that are focused only on physicians' behavior changes may well be doomed to failure if the necessary and foundational systems changes are not in place. For example, if physicians are to change their referral behaviors, the necessary referral sources and targets need to exist to accommodate such changes. If physicians are to change their practice behaviors to identify at-risk women, the necessary treatment options need to be developed to allow for appropriate intervention with such patients.

Following are various recommendations for foundational changes that need to be in existence for meaningful implementation of physician-based changes. Three foci for systems changes were developed: first, there is a focus on improving public health approaches related to FASD prevention and stigma reduction; second, there is a focus on workforce development issues, including ways to address the shortage of medical and allied health professions and lack of providers' FASD expertise; and third, there is a focus on issues associated with healthcare systems, such as reimbursement of specialized services, support for prevention activities, and augmentation of service

capacity.

Public health issues. Although public health efforts in Alaska have addressed the issue of FASD primary and secondary prevention for decades (Information Insights, 2005), findings from this study illuminated several pockets of mis- or non-information that continue to be in need of increased public awareness. Many of the related concerns and recommendations noted below align with current State of Alaska efforts to increase public awareness around FASDs.

- *Attitudes and beliefs about alcohol.* Provide funding to develop community-based alcohol prevention multi-media public awareness campaigns targeting the specific community norms and responsibilities around this health issue.
- *Education prior to pregnancy.* Disseminate education to women about preventing alcohol-exposed pregnancies through a message that addresses the danger of consuming alcohol while sexually active rather than just no alcohol consumption during pregnancy. Target these informational campaigns to all women of childbearing age (youth to adulthood), friends, partners, and families relevant to the prevention efforts. Frame the issue not as a women's issue, but as a community issue.
- *Reduction of stigma around FASD.* Address stigma currently inherent in an FASD diagnosis, stigma associated with being pregnant and using alcohol, and stigma imposed on parents of children with FASDs. Address the fact that physicians have many negative perceptions related to FASDs and make

use of the reality that physicians also recognize that societal attitudes of stigma create additional burdens for patients that get in the way of diagnostic accuracy and treatment adherence.

- *Determine the effectiveness of public health messages.* Evaluate the effectiveness, cost, and sustainability of FASD prevention campaigns and other public awareness efforts over time. Investigate the disconnect between public health messages and the behaviors (alcohol consumption during pregnancy) physicians continue to observe in their medical practices.

Workforce development. Several issues linked to workforce development emerged from this study. Many of these issues have been targeted by the State of Alaska over the past decade and align with national efforts to address the need for an adequately trained and staffed medical and allied health workforce, especially in rural and frontier states and states that have high numbers of underserved populations (Western Interstate Commission for Higher Education [WICHE] Mental Health Program, 2004). The issues and related recommendations outlined below are based on findings from this study, as well as state-level and national recommendations.

Shortage of providers. Physicians communicated frustration about the shortage of medical and allied health providers in Alaska. Underrepresented provider groups include, but are not limited to, occupational therapists, speech and language pathologists, psychologists, psychiatrists, and public health nurses. Many efforts have been undertaken by the State of Alaska to address the inadequate availability of such

medical and allied health professionals in Alaska. For example, efforts have been mounted to implement recruitment programs for medical, allied health, and behavioral health providers; create educational programs with the purpose of training Alaskan residents to fill the void in these health professions; and develop training programs tailored to increase providers' knowledge and skills around rural service provision (Alaska Physician Supply Task Force, 2006; WICHE Mental Health Program, 2004). However, workforce development takes long-term financial resources and takes years, even decades, to create healthcare systems that grow to include an adequate number of healthcare providers. In the meantime, it may be possible to provide pilot funding for new FASD medical approaches, such as medical homes and groups visits, to entice larger primary care facilities to provide comprehensive care around FASD issues (Mauer, 2009).

FASD expertise. Physicians expressed a need to have access to other medical and allied healthcare providers who specialize in FASD prevention, screening, diagnosis, and treatment, and who have the ability and willingness to work from interdisciplinary perspectives that assure comprehensive care. Although this type of training is not generally part of the educational programs for medical or allied health providers, the issue could be incorporated into training programs at all levels (from undergraduate programs to residencies and internships) and is being actively promoted by the National Task Force on FAS and FAE (Olson et al., 2009). Addressing training gaps is currently also one of the primary missions of the federally funded system of

Fetal Alcohol Spectrum Disorders Regional Training Centers (www.cdc.gov/ncbddd/fasd/training.html), one of which is currently being operated in Alaska, namely the Arctic FASD RTC (www.uaa.alaska.edu/arcticfasdrtc/).

Healthcare system issues. Several concerns emerged from this study that were related to the general operations and emphases within the current healthcare systems in the state of Alaska and the nation as a whole. Not surprisingly, many of the issues raised in this section align with greater national and state efforts to facilitate profound and far-reaching changes in the current healthcare delivery systems. The issues discussed below are based on the findings from this study, as well as grounded in published research and recommendations that have been voiced by national organizations.

Lack of service reimbursement. Physicians expressed significant concern about the lack of reimbursement for primary prevention and other FASD-related medical practices. Related to FASD prevention, physicians expressed the need for reimbursement options that cover screening and educational services related to the prevention of alcohol-exposed pregnancies. This recommendation is consistent with current efforts to establish payment options through commercial insurance carriers, Medicaid, and Medicare for physicians to conduct Screening, Brief Intervention, and Referral-to-Treatment (SBIRT) services for all patients as related to drug and alcohol concerns (Babor et al., 2007; Substance Abuse and Mental Health Services Administration, n.d.). Although SBIRT was not targeted specifically at the prevention

of alcohol-exposed pregnancies, it is a sufficiently comprehensive approach for the identification of and early intervention with persons who are misusing substances that it would provide a ready avenue for providing screening and brief intervention for women at risk for alcohol-exposed pregnancies. In addition to reimbursement for FASD prevention efforts, physicians raised the issue of needing billing options for providing services that consist of care coordination or that make use of group visits or medical home approaches. These issues are addressed in more detail below.

Medical care concerns. Physicians shared concern over what they perceived as inadequate medical care, including insufficient routine medical and prenatal care for women, as well as poor postnatal care for infants and inconsistent medical care for children. These issues are perceived to arise in part due to psychosocial challenges faced by families and, in part, due to inadequate or unavailable insurance coverage. Current statistics suggest that approximately 15% of Alaskans cannot acquire medical care due to cost and as many as 20% of non-elderly women and 13% of children are without medical coverage in Alaska (Kaiser Family Foundation, 2008). Research is clearly needed to elucidate and define the obstacles that prevent access to regular medical care in general, and more specialized services, in particular. Most likely access (or lack thereof) to specialized FASD medical services is a multi-pronged issue that has the same social, financial, personal, transportation, and geographic foundations, especially in the rural and frontier regions of Alaska, that have been identified in terms of general rural healthcare (Brems & Johnson, 2007; Chipp et al., in press).

FASD service issues. Physicians reported the need for FASD-related services for their patients. Without service providers who specialize in preventing and treating FASDs, physicians are left to patch together medical care that lacks integration, continuity, and comprehensiveness. The concerns and recommendations presented below and related to integrated, continuous, and non-fragmented care align with action steps that have been advanced by the National Task Force on FASD (Olson et al., 2009).

- *Central FASD resource system.* Create a centralized network, system, or organization that serves as a one-stop resource for easily accessible information about referrals, programs, and professionals specializing in FASD-related care throughout Alaska. Provide access to this system for all healthcare providers as well as individuals, families, and communities affected by FASDS. Place the system online for ready access and inexpensive methods of use.
- *Evidence-based FASD interventions.* Develop and test new intervention approaches that can be used with women at risk for alcohol-exposed pregnancies, for families already affected by FASDs, and for individuals throughout the lifespan who are diagnosed with FASDs. Implement existing intervention approaches for individuals with FASDs and their caregivers, including, but not limited to, medical, behavioral, pharmacological and combined treatments (e.g., Bertrand, 2009). Draw upon existing literature

(e.g., Namyniuk, Brems, & Clarson, 1997) to build comprehensive care plans that wrap around each individual and family affected by FASDs and explore the feasibility and effectiveness of such systems through systematic, adequately-funded research.

- *FASD services for adults.* Develop medical and behavioral healthcare programs for adults who experience FASDs. Adapt eligibility for existing vocational and supported housing services to include adult individuals diagnosed with FASDs. Educate medical and allied healthcare providers about the continued healthcare needs of adults who were diagnosed with FASDs during childhood, ensuring that individuals do not age out of the healthcare system without ongoing supports for physical and mental health.
- *FASD continuum and continuity of care.* Develop and implement a continuum of care model of validated or promising FASD-specific practices that address the full range of needs of children, adolescents, and adults who experience FASDs. Build medical homes that oversee and track the healthcare of affected individuals and their families and caregivers. Build group practice approaches that allow for social contacts and emotional supports, while providing important medical care. Build integrated systems that support the individuals who have been diagnosed with FASDs, their caregivers and families, and their medical and allied healthcare providers. Develop mechanisms for care navigation that transcend individual provider

offices, ensuring that each individual and family affected by FASDs has a single point of contact who helps coordinate their care across systems and providers in a transdisciplinary manner.

Practice Improvement Recommendations

Based on findings from Phases One and Two, recommendations for improving physicians' FASD-related practice were developed. They focus on improving FASD practices related to prevention, screening and recognition, diagnosis, and long-term care. More specifically, practice recommendations offer ideas about utilization of universal screening for alcohol use among women of childbearing age, about the use of brief interventions for targeting alcohol consumption during pregnancy, and about adherence to nationally recognized guidelines for providing FASD screening, diagnostic, and intervention services.

Universal screening for alcohol use among women of childbearing age. Although physicians appear committed to screening pregnant women for alcohol use, no process exists for universal screening, either for women of childbearing age or for assessing alcohol consumption. Although a challenge, physicians would benefit from learning about and implementing screening methods that have been identified as effective and reliable through research efforts. This simplest form of screening that can occur for *all* women consists of questions about quantity and frequency of alcohol use, as recommended by the physicians' guide developed by NIAAA (1999). These questions include number of days per week of any alcohol consumption, average

number of standard drinks per day, and maximum number of standard drinks consumed during a single day within the last month.

To assess risky drinking patterns, the most commonly used standardized questionnaires for adult women of childbearing age and pregnant women are the T-ACE (Tolerance, Annoyed, Cut down, and Eye-opener) and the TWEAK (Tolerance, Worried, Eye-opener, Amnesia, and K/Cut down) self-report instruments (O'Connor et al., 2009). With regard to screening sensitivity, the T-ACE has been shown as reliable in assessing lifetime alcohol diagnosis, risky drinking, and current alcohol use (Bradley, Boyd-Wickizer, Powell, & Burman, 1998). For screening adolescents and college-age women, the CRAFFT (Car driven, Relax, Alone, Forget, Family or Friends, and Trouble) is considered an effective brief tool to screen for alcohol and drug use among young women age 14 to 18 (Knight, Shrier, & Bravender, 1999).

Use of brief interventions to reduce alcohol-exposed pregnancies. Physicians seem to understand and accept that they play an important role in the prevention of alcohol-exposed pregnancies; however, this study, as well as others, suggests that physicians are neither adequately trained nor comfortable intervening with women at risk for an alcohol-exposed pregnancy. This reluctance exists despite the fact that promising practices that reduce the risk of prenatal alcohol exposure have been documented. For example, studies report positive results with brief motivational interventions for preventing prenatal alcohol exposure (Floyd et al., 2007; Handmaker & Wilbourne, 2001; Project CHOICES Research Group, 2002). Participant groups for

whom effectiveness has been demonstrated include female college students, non-pregnant women of child-bearing age, and pregnant women. Settings have included university (Ingersoll et al., 2005), medical and community health (Project CHOICES Research Group, 2002; and Handmaker & Wilbourne, 2001; Project Choices, 2002), and substance abuse treatment environments (Handmaker, Miller, & Manicke, 1999). Given the potential positive outcomes related to the use of brief motivational interventions to prevent FASDs and physicians' desires to learn more effective means for working with women around FASD prevention, physicians could benefit from learning to implement brief motivational interventions in their prevention practices.

FASD screening and recognition practice recommendations. Physicians acknowledged that they have an important role in FASD screening and recognition; however, they find it challenging to engage in accurate screening of children who do not possess the growth deficiencies and facial characteristics of FAS. Although physicians voiced frustration over the lack of a standardized FASD screening process, guidelines do exist to support physicians in screening for FAS and FASDs. It is important for physicians to learn about and implement the Centers of Disease Control and Prevention recommendations for FASD screening (Bertrand et al., 2004). Physicians need to have a solid understanding of triggers that should prompt a diagnostic process, including developmental problems, facial abnormalities, growth delays, and evidence or suspicion of maternal alcohol use. It is vital that physicians have a grasp of the functional deficits that may be found among children experiencing

FASDs, such as the cognitive, executive functioning, motor functioning, social skills, and attention deficits outlined in Chapter Two.

Fortunately, physicians' desire for a standardized screening process may soon become a reality. Efforts are underway in Canada to develop an FASD screening toolkit. Preliminarily findings suggest that a battery of five tests may support physicians in determining the need to refer an individual for a full FASD diagnostic assessment (Goh et al., 2008). These five tools include a screening for fatty acid ethyl esters in neonatal meconium (Chan, Klein, & Koren, 2004), the modified Child Behavior Checklist (Achenbach, 1991), Medicine Wheel Tool, Asante Centre Probation Officer Tool (Canadian Association of Peadiatric Health Centres, 2008), and maternal history of drinking and alcohol use (Brimacombe et, al., 2009). The developers of this protocol recommend that physicians learn about and implement screening tools to improve their ability to screen for alcohol-related birth defects that fall outside the criteria for a full diagnosis of FAS (Goh et al., 2008).

FASD diagnostic practice recommendations. With regard to diagnosis, physicians view their role as facilitators of the process of securing a diagnostic assessment, rather than rendering diagnostic services or diagnoses. Physicians appear more likely to conduct diagnoses in straightforward cases (i.e., in the presence of prenatal alcohol exposure, growth deficiencies, and facial dysmorphology) or if they are the only provider available to make a diagnosis, such as in a rural community. Unfortunately, given the prevalence data about FAS and FASDs in Alaska, most

Alaskan physicians will encounter a child, youth, or adult in their practice who was prenatally exposed to alcohol and would benefit from an FASD diagnostic assessment. Therefore, physicians, especially pediatricians and family practice physicians, need foundational knowledge of the criteria and procedures for initiating or completing an FASD diagnosis.

As an important aspect of accurate screening and diagnosis (or even diagnostic referral), effective communication with caregivers is a crucial skill for physicians who may be faced with this work. It is recommended that physicians learn how best to communicate with caregivers around this emotional subject whose discussion often results in feelings of guilt, shame, sadness, and loss. The manner in which physician-parent consultation is conducted can greatly facilitate or hinder the diagnostic process as well as ongoing pediatric care. The recommendation of maintaining effective communication between physician and caregiver is consistent with training provided in developmental-behavioral pediatric textbooks (Levine, Carey, & Crocker, 1999). Working from a position of collaboration and openness in communication, as promoted in the field of developmental-behavioral pediatrics, seems especially important for physicians to implement with caregivers when dealing with evaluations prompted by alcohol exposure in utero.

FASD ongoing medical practice recommendations. When physicians identify their role in maintaining long-term medical care for individuals experiencing FASDs, two main practice areas emerge as important in supporting positive outcomes for these

patients. These practice areas include care coordination and use of newer medical provision approaches, such as medical homes and group visits.

Care coordination. Based on findings of this study and well-established practice recommendations (Council on Children with Disabilities, 2005), care coordination requires several steps, including: 1) assessing the individual's needs; 2) identifying medical specialists (i.e., developmental pediatrician, psychiatrist), other health providers (i.e., occupational therapist, speech and language pathologist, mental health counselor, social workers, parent advocates), or programs (i.e., infant learning program, special education, parent support groups); and 3) maintaining communication with providers to assess progress. Effective and comprehensive care coordination leads to improved access to services, continuity of care, family support, and advocacy for children with special medical needs (McAllister, Presler, & Cooley, 2007). Care coordination for individuals with FASDs can have life-altering benefits in the short and long term.

Medical homes. Physicians within this study discussed their roles in assuring long-term medical care for individuals experiencing FASDs in the context of long-term, multidisciplinary care management and coordination. This notion aligns with medical care experts who promote a paradigm shift by physicians toward the integration of behavioral health and primary care and embraces the movement within healthcare systems to develop person-centered medical homes with integrated behavioral health and primary medical care services (Mauer, 2009). The treatment of brain-based

physical disabilities, such as FASDs, fits particularly well within this innovative medical practice paradigm. In fact, the medical model approach is endorsed by the American Academy of Pediatrics as a comprehensive way to provide treatment to individuals who experience complex disabilities needing the support of a medical home model, such as FASDs (AAP, 2002). Although most physicians in this study did not use the term *medical home*, the role and responsibilities they outlined related to care coordination seemed to capture the very essence of the medical home model.

Group visits. Although mentioned less often by respondents in this study, the use of a group visit was suggested by a subset of the physicians as a means to provide more intensive care for FASDs. A group visit, also known as a shared medical appointment, includes a medical examination along with group education. During a group visit, multiple patients are seen as a group for follow-up or routine care. According to the American Academy of Family Physicians, such visits provide patients with a secure, interactive setting with improved access to physicians; the benefit of counseling or consultation with additional healthcare providers (e.g., behaviorists, nutritionists, or health educators); and the opportunity to share experiences and advice with other patients (Masley, Sokoloff, & Hawes, 2000).

With regard to ongoing care for adults who experience FASDs, physicians who adopt comprehensive care coordination strategies, medical home models, or group visit structures would likely develop more effective care systems for this difficult-to-treat population as they would draw upon the support of behavioral and other allied health

specialists. Such access to ancillary care results in enhancing patients' understanding of their health status and supporting them in following medical regimes and recommendations (Namyniuk, Brems, & Clarson, 1997). Unfortunately, little research has been done on effective treatments for adults experiencing FASDs. Currently, recommendations for caring for adults are limited to general supports, such as case management, vocational rehabilitation, transportation assistance, and employment coaching and lack specific guidelines for physicians (Mitchell et al., 2009).

FASD Curriculum Recommendations

According to the findings of this study, Alaskan physicians recognize the importance of having opportunities to learn about FASD practices through continuing education. Educational opportunities for physicians are viewed as best offered through various media, tailored to often-challenging schedules and time limitations. Several curriculum content areas emerged from the data that could be tailored to meet training needs of physicians. These recommendations relate to four main areas: basic FASD-related educational needs, FASD prevention, FASD screening and diagnosis, and FASD long-term care.

Basic FASD-related educational needs. Although physicians appear to be generally knowledgeable about the consequences of alcohol consumption during pregnancy, deficits in their knowledge will most likely affect the approach they take to FASD prevention and the accuracy of information they provide to patients. Findings suggest that continuing medical education for physicians will be beneficial to assure a

universal understanding of basic risks of alcohol consumption by pregnant and breastfeeding women. More specifically, the following FASD-related findings are recommended for inclusion in FASD curricula or educational materials for Alaskan physicians (Brimacombe et al., 2009):

- No known amount of alcohol consumption is safe during pregnancy;
- No period during pregnancy appears safe for alcohol consumption; and
- Alcohol consumption during breastfeeding is associated with negative outcome for the infant (e.g., deficits in gross motor movements and poor suckle response).

FASD prevention. Physicians recognize that they have an important role in FASD prevention with their patients. Based on physician responses, responsibilities include screening for alcohol use by women (of childbearing age, pregnant, and/or breastfeeding); educating and counseling women about consequences of consuming alcohol during pregnancy and breastfeeding; and referring women to substance abuse treatment services, as needed. In developing training materials about FASD prevention for physicians, case examples are necessary to make information as practical as possible to help them better translate information into practice behavior changes. The following curriculum content areas are based on physicians' needs gleaned from this research study and based on existing literature identified in each content area.

- *Universal alcohol screenings.* It is important to train physicians in how to utilize standardized questionnaires for conducting universal alcohol

screenings for women of childbearing age and pregnant women. Recommended tools include, but are not limited to, the T-ACE, TWEAK, and CRAFFT (O'Connor et al., 2009).

- *FASD prevention with women of childbearing age.* It is important to provide physicians with practical education through case examples and role-plays on how to communicate with women of childbearing age about the consequences of alcohol consumption when sexually active and not using reliable contraception. One evidence-based model for effective communication around FASD prevention is the Centers for Disease Control and Prevention-funded Project Choices (Changing High-risk Alcohol Use and Increasing Contraception Effectiveness Study) that utilizes a brief motivational intervention approach (Project CHOICES Research Group, 2002).
- *FASD prevention with pregnant women.* It is important to provide physicians with practical education through case examples and role-plays on how to communicate with pregnant women about prenatal and postnatal consequences of alcohol consumption. A promising practice model for this is the NIAAA-funded Project Care that utilizes a brief motivational intervention approach for pregnant women (O'Connor & Whaley, 2007).
- *Clinical conceptualization of alcohol addiction.* It is important to provide education and training to physicians with the goal of increasing their

understanding of alcohol addiction from a biomedical rather than a moral model, as well as the role of genetics and environmental factors in alcohol dependency and the value of harm-reduction approaches (Adubato, Mitchell, & Rupp, 2009).

FASD screening and diagnosis. Physicians within this study clearly acknowledged the importance of their role in screening for FASDs and referring for diagnostic assessments. However, at least partially due to a lack of specialized training, they did not feel confident in their ability to either render diagnoses or to make an appropriate referral for diagnosis, partially due to a lack of specialized training. The following recommended curriculum content areas are based on physicians' needs as identified through this research study and the existing literature noted in each content area.

- *Initial recognition of FASDs.* It is important to provide training and education to physicians regarding clinical triggers that should prompt a referral for FASD diagnosis, including developmental problems, facial abnormalities, growth delays, evidence or suspicion of maternal alcohol use, as well as functional deficits. Functional deficits that should stimulate consideration of diagnostic referral include, but are not limited to, cognitive impairment, executive functioning, motor functioning, social skills, and attention deficits (Bertrand et al., 2004).
- *Use of FASD screening tools.* It is important to help physicians keep current

with current screening procedures for the initial recognition of FASDs. Screening tools can improve physicians' ability to check for alcohol-related birth defects that fall outside the criteria for a full diagnosis of FAS. The Canadian Association of Paediatric Health Centres' *FASD Screening Tool Development Project* has developed and is in the process of testing a universal process for FASD screening that includes tests for fatty acid ethyl esters in neonatal meconium test, the modified Child Behavior Checklist, Medicine Wheel Tool, Asante Centre Probation Officer Tool, and maternal history of drinking and alcohol use (Goh et al., 2008).

- *FAS and FASD diagnostic criteria and processes.* It is important to provide training and education to physicians about basic criteria and procedures for diagnosing FAS and FASDs (Bertrand et al., 2004). For example, education needs to include processes for referral to multidisciplinary diagnostic teams in Alaska or for receiving specialized training in conducting a diagnostic assessment in the method adopted by Alaska (University of Washington Four-Digit Code; Astley & Clarren, 1999).
- *Communication with individuals and caregivers around FASDs.* It is important to provide physicians with practical education through case examples and roleplays on how to communicate collaboratively with caregivers regarding evaluations prompted by alcohol exposure *in utero*. For example, communication skills from the literature on reflective listening

skills, brief motivational intervention skills, or patient-center care models would support physicians in following through on talking about difficult and emotionally charged issues (Mauer, 2009; O'Connor & Whaley, 2007).

FASD long-term care. When physicians discussed their role in providing long-term medical care for individuals experiencing FASDs, they emphasized the importance of care coordination and use of newer medical provision approaches, such as medical homes and group visits. These findings are in alignment with the 2007 American Academy of Pediatrics Call to Action, appealing to physicians to address individuals with FASDs as they would other patients with complex disabilities. The following curriculum content areas are based on physicians' needs as identified through this research study and the existing literature noted in each content area.

- *Multidisciplinary care*. It is important for physicians to understand the benefits of a multidisciplinary approach to FASD treatment and to be educated on effective strategies for referral and coordination of this form of medical care. A multidisciplinary approach incorporates various treatment modalities to address the wide range of functional deficits associated with FASDs, including, but not limited to, occupational therapists, speech and language pathologists, and psychologists (Mitchell et al., 2009).
- *Care coordination*. It is important to provide training and education for physicians on effective strategies for coordinating care for individuals experiencing FASDs and their caregivers. This level of care coordination

includes, but is not limited to, identifying multidisciplinary care needed for improved patient outcomes, securing services and assuring follow-through, and managing outcomes of services across multiple providers (McAllister et al., 2007). Proactive care coordination and care planning are fundamentally essential for improved care quality, access to services and resources, health and function of children and youth, quality of life, and improved systems of care.

- *Medical homes.* It is important to provide training and education to physicians to support a paradigm shift around the innovative movement toward medical homes. This education should include, but not be limited to, key factors in developing a medical home to provide and coordinate care and insure necessary medical, behavioral, social, and educational services for individuals experiencing FASDs. Successful medical homes are most likely to result from partnerships with families that offer fully-implemented, practice-based care coordination.
- *Group visits.* It is important to provide training and education to physicians regarding the use of group visit paradigms to provide intensive and comprehensive care for individuals with FASDs. Group visits, also known as shared medical appointments, include a medical examination along with group education. Group visits have been shown to improve patient outcomes through increased patient-physician interaction and

communication, opportunity for answering patient questions and addressing health concerns, and patient empowerment around health behavior change (Masley et al., 2000).

- *FASD care for adults.* It is important to provide guidance and support to physicians in caring for adults experiencing FASDs. Currently, there is little research addressing this treatment issue. Providing physicians with ideas for adapting current medical practices to serve existing adult patients with brain-based physical disabilities is imperative. For example, helping physicians to recognize the utility of adapting care coordination, medical home models, and group visits could greatly enhance their services to adults who experience FASDs. Adaptation could include creating medical care systems that allow physicians to coordinate adults' care related to health behavior change, mental health, vocational rehabilitation, transportation assistance, and employment coaching (Mitchell et al., 2009).

Future Research Considerations

Given the results of this explanatory mixed methods study, the need for more research that provides guidance to physicians for FASD-related practices is evident. Physicians identified the importance of reaching women during adolescence with education and counseling around alcohol use and pregnancy. To support them in this effort, research needs to investigate how physicians can best approach FASD prevention, either through universally-delivered educational messages or by targeting

teens at risk for pregnancy and alcohol use.

Physicians also need guidance on how to screen, diagnose, and treat adult patients who experience FASDs. A dearth of research related to adults with FASDs has a negative impact on physicians' understanding of how best to provide FASD screening and diagnostic services, as well as adapt standard medical approaches for adult patients who have brain-based physical disabilities, such as FASDs. Generally, more research is needed to help bridge the gap between FASD-related scientific knowledge and the development of clinical practice protocols for physicians that could improve the health and wellbeing of patients. Easy access to referral targets and practical FASD-related protocols would greatly support efforts to improve FASD prevention, recognition, diagnosis, and treatment by medical professionals, especially pediatricians, OB/GYNs, and family physicians.

In addition to the above FASD-related research gaps, there is a need to utilize mixed methods research in medical and behavioral health settings. With the recent growth in the acceptance of qualitative research in the healthcare field (O'Cathain et al., 2007), it seems a natural process to move beyond using a single method and to start integrating quantitative and qualitative methodologies. The current mixed methods study endeavored to integrate quantitative and qualitative findings to draw informed conclusions and make purposeful recommendations for improving FASD primary and secondary prevention practices by Alaskan physicians. Other mixed methods research could help narrow the gap between the understanding of the scientific knowledge of

physicians and their practice behaviors, as well as between patient knowledge and their ability to change health behaviors related to FASD prevention, recognition, diagnosis, and treatment.

Summary

Through participation in this study, Alaskan physicians shared their perceptions and opinions about systemic and professional barriers that affect their clinical practice, educational and training needs related to primary and secondary prevention, and service gaps and access challenges that impede FASD-related practices. To fulfill the roles that they have identified for themselves around FASD-related practices, physicians need support in many areas, including but not limited to: 1) specialized education during medical school and residency; 2) easily accessible continuing education opportunities; 3) development and dissemination of best practice protocols related to FASD care; 4) workforce development to increase referral options for patients; and 5) changes to healthcare systems to support primary and secondary prevention practices. Many of the challenges and obstacles outlined by physicians are beyond their control and need to be addressed not only as independent practice issues but as larger medical education and healthcare system issues. Given these realities and findings, the study outlined suggestions and resources for physicians related to needed changes in their FASD-related practice behaviors and provided recommendations about how university/medical schools and state and federal entities can better support physicians' efforts to reduce and treat this entirely preventable birth defect.

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Appendix A

Knowledge, Attitudes, Behaviors, and Beliefs (KABB) Survey

State of Alaska
Department of Health and Social Services
Office of Fetal Alcohol Syndrome
350 Main Street, Suite 214
Juneau, AK 99811-0620

Fetal Alcohol Syndrome in Alaska

Statewide Survey of Physicians' Opinions And Clinical Experiences

We are seeking information from physicians about their thoughts and experiences regarding alcohol use among their patients and Fetal Alcohol Syndrome (FAS). Your responses will be used to let policymakers know your views on the role of physicians in addressing Fetal Alcohol Syndrome among their patients and to develop continuing medical education resources.

This survey takes 10 minutes or less to complete. Please return your completed survey in the enclosed stamped envelope. Thank you for your time and expertise.

1. In your opinion, is it okay for a pregnant woman to have an occasional alcoholic beverage? ☐ Yes ☐ No ☐ No Opinion

2. What do you think is the most alcohol that a woman could drink during her pregnancy that would probably be safe for her developing baby?

0 drinks during her pregnancy	1 or 2 drinks during her pregnancy	3 or 4 drinks during her pregnancy	5 or more drinks during her pregnancy	Don't Know
☐	☐	☐	☐	☐

3. When do you think that a woman could drink during her pregnancy that would probably be safe for her developing baby?

Never during her pregnancy	During her 1st trimester	During her 2nd trimester	During her 3rd trimester	Don't Know
☐	☐	☐	☐	☐

4. In your opinion, is it okay for a nursing mother to have an occasional alcoholic beverage? ☐ Yes ☐ No ☐ No Opinion

5. Do you think it's her own business if a woman drinks alcoholic beverages during her pregnancy? ☐ Yes ☐ No ☐ No Opinion

6. With the next five statements please indicate how likely it is that you would talk to a pregnant friend or relative about the effects of alcohol on a developing baby if:

	Highly Likely	Likely	Unlikely	Highly Unlikely	Don't Know
a) Your friend or relative drank 1 or 2 alcoholic beverages during her **entire** pregnancy.	☐	☐	☐	☐	☐
b) Your friend or relative drank 1 or 2 alcoholic beverages **a month** during her pregnancy.	☐	☐	☐	☐	☐
c) Your friend or relative drank 1 or 2 alcoholic beverages **a week** during her pregnancy.	☐	☐	☐	☐	☐
d) Your friend or relative drank 1 or 2 alcoholic beverages **a day** during her pregnancy.	☐	☐	☐	☐	☐
e) Your friend or relative drank **5 or more** alcoholic beverages on any one occasion during her pregnancy.	☐	☐	☐	☐	☐

YOUR COMMENTS AND SUGGESTIONS ARE IMPORTANT TO US. PLEASE FEEL FREE TO WRITE ANYWHERE ON THIS QUESTIONNAIRE AND/OR CALL DIANE CASTO AT 465-3033 (IN JUNEAU) OR (877) 393-2287 (OUTSIDE JUNEAU)

7. With the next five statements, please indicate how likely it is that you would talk to a pregnant friend or relative about seeking professional services to help her stop drinking if:

	Highly Likely	Likely	Unlikely	Highly Unlikely	Don't Know
a) Your friend or relative drank 1 or 2 alcoholic beverages during her **entire** pregnancy.	☐	☐	☐	☐	☐
b) Your friend or relative drank 1 or 2 alcoholic beverages **a month** during her pregnancy.	☐	☐	☐	☐	☐
c) Your friend or relative drank 1 or 2 alcoholic beverages **a week** during her pregnancy.	☐	☐	☐	☐	☐
d) Your friend or relative drank 1 or 2 alcoholic beverages **a day** during her pregnancy.	☐	☐	☐	☐	☐
e) Your friend or relative drank **5 or more** alcoholic beverages on any one occasion during her pregnancy.	☐	☐	☐	☐	☐

8. How much do you know about the medical diagnosis called Fetal Alcohol Syndrome?

☐ I've never heard of FAS ☐ I've heard of FAS ☐ I know a little bit about FAS ☐ I know a lot about FAS

9. Please indicate how strongly you agree or disagree with the next six statements about Fetal Alcohol Syndrome (FAS):

	Strongly Agree	Somewhat Agree	Somewhat Disagree	Strongly Disagree	No Opinion
a) People with FAS have a set of birth defects.	☐	☐	☐	☐	☐
b) People with FAS have brain damage.	☐	☐	☐	☐	☐
c) People with FAS have mental retardation.	☐	☐	☐	☐	☐
d) People with FAS are affected physically.	☐	☐	☐	☐	☐
e) People with FAS will outgrow these effects.	☐	☐	☐	☐	☐
f) People with FAS have these effects through adulthood.	☐	☐	☐	☐	☐

10. Please indicate how strongly you agree or disagree with the next six statements about the effects of FAS on a person's capabilities:

	Strongly Agree	Somewhat Agree	Somewhat Disagree	Strongly Disagree	No Opinion
a) FAS affects a person's motor skills.	☐	☐	☐	☐	☐
b) FAS affects a person's memory.	☐	☐	☐	☐	☐
c) FAS affects a person's judgment.	☐	☐	☐	☐	☐
d) FAS affects a person's ability to plan.	☐	☐	☐	☐	☐
e) FAS affects a person's ability to reason.	☐	☐	☐	☐	☐
f) FAS affects a person's ability to learn.	☐	☐	☐	☐	☐

11. Please indicate how strongly you agree or disagree with the next three statements about alcohol use and FAS:

	Strongly Agree	Somewhat Agree	Somewhat Disagree	Strongly Disagree	No Opinion
a) Drinking alcohol during pregnancy can cause birth defects.	☐	☐	☐	☐	☐
b) Currently, the only known cause of FAS is alcohol consumption by a birth mother during her pregnancy.	☐	☐	☐	☐	☐
c) Fetal Alcohol Syndrome is preventable.	☐	☐	☐	☐	☐

12. Are you aware of any local groups or state agencies who currently provide help with FAS issues in your community? ☐ Yes ☐ No

12a. If yes, who are they?_____

13. Which of these populations do you currently provide services for? (Please check all that apply)

children (ages 12 or less)		adolescents (ages 13-18)		adults (ages 19+) currently	
☐ Male	☐ Female	☐ Male	☐ Female	☐ Male	☐ Female

14. Of your current female patients, what percent do you know, or strongly suspect, are pregnant?..... _____%

15. Of these patients who are, or likely pregnant, what percent do you strongly suspect to have an alcohol problem?..... _____%

16. Of the newborn patients that you have delivered or seen in the past year, what percent have had alcohol-related complications?..... _____%

17. Do you currently have any FAS screening or diagnostic services available in your community? ☐ Yes ☐ No ☐ Don't Know

17a. If yes, who are they? _____

18. Please indicate whether or not you have ever:

	Yes	No
a) Referred a patient for an FAS screening or diagnosis?	☐	☐
b) Referred the child of a patient for an FAS screening or diagnosis?	☐	☐
c) Made an FAS chart notation on a patient?	☐	☐
d) Made an FAS diagnosis on a patient?	☐	☐

19. When providing treatment for your patients, how often do you:

	Always	Most of the time	Some of the time	Never
a) Ask your pregnant patients if they use alcohol?	☐	☐	☐	☐
b) Inform your pregnant patients about the effects of alcohol on a developing baby?	☐	☐	☐	☐
c) Refer pregnant patients who have alcohol abuse problems to a treatment or counseling program?	☐	☐	☐	☐

20. During the past year when you delivered the babies of women that you knew or strongly suspected to have alcohol abuse problems, how often did you note alcohol use on the birth record of those babies?

Always	Most of the time	Some of the time	Never
☐	☐	☐	☐

PLEASE TURN PAGE

21. Please indicate how strongly you agree or disagree with the following statements about your role as a health care provider:

	Strongly Agree	Somewhat Agree	Somewhat Disagree	Strongly Disagree	No Opinion
a) I feel that it is important for family physicians to address alcohol abuse problems among their patients and families.	☐	☐	☐	☐	☐
b) I feel comfortable making a chart notation of Fetal Alcohol Syndrome (FAS).	☐	☐	☐	☐	☐
c) I feel comfortable making a diagnosis of Fetal Alcohol Syndrome (FAS).	☐	☐	☐	☐	☐
d) I feel that I have the appropriate skills and knowledge to deal with patients and their families who have problems with alcohol abuse.	☐	☐	☐	☐	☐
e) I feel that I have the appropriate skills and knowledge to deal with patients who have FAS.	☐	☐	☐	☐	☐

22. What is the primary setting for your practice:

Hospital-based Practice	Native Health Corporation	State/Borough/ Municipality	Military	School	Private Practice	IHS	Other (Specify) _____
☐	☐	☐	☐	☐	☐	☐	☐

23. In a typical week, how many patients do you see? _____

24. Where is your main work location (city or village name)? _____

25. Does your work require that you travel to other locations besides your main work site? ☐ Yes ☐ No

26. In what year did you graduate from medical school? _____

27. How many years of experience do you have as a physician? _____

How many of these years have been in Alaska? _____

28. What is your gender? ☐ Male ☐ Female

29. In what year were you born? _____

30. What kinds of support would be helpful to you in dealing with patients who have FAS?

31. What expertise or strengths do you have for dealing with patients who have FAS?

THANK YOU FOR YOUR HELP

Appendix B

KABB Survey Internal Review Board Approval Letters

UAA UNIVERSITY *of* ALASKA ANCHORAGE
Office of Academic Affairs

December 8, 2005

Dr. Mark E. Johnson
Behavioral Health Research and Services
3401 East 42nd Street, Suite 201
Anchorage, Alaska 99508

Dear Dr. Johnson:

Your study entitled *FAS Knowledge, Attitudes, Behaviors and Beliefs (KABB) Survey* meets the requirements in 45 CFR 46, '46.101(b) as being exempt from full Institutional Review Board review and is approved.

Therefore, you have permission to begin data collection for your study. If this study goes beyond one year from the date of this submission, you will need to submit the necessary forms for a continuation.

On behalf of the Board, I want to extend my best wishes to you for success in accomplishing the objectives of your study.

Sincerely,

Joanne K. Thordarson, MS
IRB Research Administrator

cc: Barbara Tullis, Faculty Services Manager
Dean James Liszka, College of Arts and Sciences

UAA UNIVERSITY of ALASKA ANCHORAGE

Office of Research and Graduate Studies

November 30, 2006

Dr. Mark Johnson
Behavioral Health Research and Services
University of Alaska Anchorage
3211 Providence Drive
Anchorage, Alaska 99508-4614

Dear Dr. Johnson:

This letter is in response to your request for continued Institutional Review Board (IRB) approval of your research project entitled *FAS Knowledge, Attitudes, Behaviors and Beliefs (KABB) Survey.*

This project was originally reviewed by the IRB in December 2005. Your progress report states that you have had no problems with data collection and would like an extension of IRB approval. Your request is granted.

Should data collection extend beyond one year from the date of this letter, please submit the necessary forms for continuation of IRB approval, and a final report on the project at its close.

On behalf of the entire Board, I wish you continued success with your research.

Sincerely,

Claudia Lampman

Claudia Lampman, Ph.D.
Chair, Institutional Review Board

cc: Barbara Tullis, Faculty Services Manager
Dean James Liszka, College of Arts and Sciences

Appendix C

Key Informant Consent Form

Medical Providers' Perceptions about
Fetal Alcohol Spectrum Disorders in Alaska

Researcher:
Sarah Dewane, SarahD@uaa.alaska.edu
Clinical and Community Psychology PhD Program
University of Alaska Anchorage and Fairbanks
Office- (907) 317-1426 or (907) 561-2880

Research Supervisor:
Dr. Chris Brems, afcb@uaa.alaska.edu
University of Alaska Anchorage
Dissertation Chair
Office- (907) 561-2880

PURPOSE AND BACKGROUND

As a doctoral student in the Clinical and Community Psychology Program, I am conducting a study exploring Fetal Alcohol Spectrum Disorder (FASD) prevention, intervention, and treatment practices among OB/GYN, pediatrics, and family practice physicians who are currently practicing in Alaska. You are invited to participate in this study because you meet the above criteria. You were selected for this study because your name was provided by another medical provider as a possible participant or because you were selected from a random selection of the Alaska State Medical Association Directory.

The study is seeking your opinions and perceptions about FASD in Alaska. If you choose to participate, you will be interviewed for about 45 to 60 minutes at a location that is mutually convenient for you and the researcher. You will be asked your views and experiences regarding prevention, intervention, and treatment of FASD in Alaska. I will make notes and the interview will be audio-taped. The recording will be used only to assure accurate data collection and for data analysis purposes. The tape will be destroyed one year after all analysis and manuscripts have been completed and distributed.

CONFIDENTIALITY

Your responses in the interview will be confidential. All the materials from this study, including the written notes and audiotape, will be kept in a secure file cabinet in the researchers' office to which only they have access. Data will be compiled in such a way that you cannot be identified. We will not attach your name, address, or any other identifiable information about you to any of your responses, or to any reports or publications describing the results of this study. Though direct quotes from you may be used in the results of this study, your name and other identifying information will be kept anonymous.

VOLUNTARY NATURE OF PARTICIPATION:

Your participation in this study is voluntary. You may stop at any time and you do not have to answer any questions you do not want to. You may choose not to answer any questions or you may decide not to participate.

COSTS AND COMPENSATION
There are no financial costs to you for participating in this study. You will receive a $50 gift certificate for your time and efforts in participating in this study.

POTENTIAL BENEFITS AND RISKS
Your participation in this study only requires a commitment of time on your part. However, if you decide to participate, your willingness to share your experiences and knowledge may provide valuable insights for increasing our understanding about how better to engage in FASD prevention. There are no foreseeable risks or direct benefits to you personally or professionally from participation in this study.

QUESTIONS
If you have any questions about this study, please contact Sarah Dewane at (907) 317-1426 or Dr. Chris Brems, Dissertation Chair, at (907)561-2880. If you have any questions or concerns about your rights as a research participant, please contact Dr. Robert White, the UAA Vice Provost for Research and Graduate Studies, at (907) 786-1099.

SIGNATURE
Informed consent will be collected before a participant can begin the interview. No names are collected from participants at any time, except on the informed consent document. Consent will be provided by participants signing that they understand and agree with the following statements:

- *I have read or listened to the information on this consent form.*
- *I understand what is in the consent form and had opportunity to ask questions.*
- *I understand that the study is completely voluntary.*
- *I understand that I can quit at any time.*
- *I would like to participate in this study.*

With my signature below, I indicate that I understand and agree with all of the above statements:

Signature_____ Date _____
Print Name _____

Appendix D

Key Informant Interview Protocol

Medical Providers' Perceptions about
Fetal Alcohol Spectrum Disorders in Alaska

Interview Date:	Location:
Time Started:	Time Ended:
Interviewer:	Dates and Types of Contacts:
Remarks:	

Point 1

- It is the purpose of this study to begin to accumulate information about Alaskan physicians' experiences with and needs related to engaging in primary and secondary prevention of FASD.
- The study will examine physicians' level of knowledge, attitudes, practices, and understanding related to FASD to identify effective ways to educate and train physicians about FASD primary and secondary prevention in Alaska

Point 2

Administer and review the informed consent

- Do you have any questions for me regarding the informed consent?
- As stated in the informed consent, I would like to record our conversation.
- Once the interview is done, the recording is used strictly to transcribe what your answers were, but without identifying who you are personally.
- Do you have any questions about the recording?

Start tape

Interview Questions

1. *From your perspective, what is a physicians' role in FASD prevention?*
2. *In what ways do physicians talk to women about FASD prevention?*
3. *From your perspective, what is a physicians' role in FASD diagnosis, treatment, referral, ongoing medical care, and monitoring of care?*
4. *In what ways do physicians address FASD diagnosis, treatment, referral, ongoing medical care, and monitoring of multidisciplinary care?*
5. *What systemic and professional barriers do physicians encounter when engaging in FASD prevention, diagnosis, and intervention efforts in Alaska?*
6. *How does stigma influence physician practices related to FASD?*
7. *What would help increase physicians' comfort and skill related to engaging in*

FASD prevention, diagnosis, and intervention efforts in Alaska?

8. *What specific educational and training needs do physicians have in related to FASD?*
   Prompt: what strategies might be most helpful?
9. *What are you thoughts on FASD-related service accessibility and gaps in Alaska?*
10. *Do you have any other thoughts or experiences that you would like to share about physician practices related to FASD prevention?*

Respondent demographics

Gender (Circle): *Female* *Male*
Age (in years):
Ethnicity/Race:
Position and Degree:
Years of Experience:
Year of Experience in Alaska:
Medical Specialty Areas:

Closure

Complete Data: Check to see that you have complete data; be sure that every major question was covered.

Consent Form: Make sure the participant has a copy of the consent form and has the name and phone number of relevant project staff should the participant want additional information about the study or thinks of something later.

- I really appreciate that you were willing to talk to me.
- The information you gave me is going to be very helpful.
- Thank you very much for your time.

Stop tape

Appendix E

State of Alaska Permission to Use Archival Data

STATE OF ALASKA
Department of Health and Social Services
DIVISION OF BEHAVIORAL HEALTH

SARAH PALIN, GOVERNOR

P.O. Box 110620
JUNEAU, ALASKA 99811-0620
PHONE: (907) 465-3370
FAX: (907) 465-2668

December 16, 2008

Sarah Dewane, M.S., L.P.A.
University of Alaska Anchorage
P.O. Box 241626
Anchorage, AK 99524-1626

Re: Authorization for Use of KABB Data

Dear Ms. Dewane:

This letter provides authorization for you to utilize the FASD KABB data as a component of your dissertation requirements. I have a clear understanding of your study, entitled *Medical Providers' Perceptions about Fetal Alcohol Spectrum Disorders in Alaska,* and I am in support of its completion. Per our discussion, I am aware of the IRB procedures for reviewing research projects and grant you permission to present this letter to the IRB, as well as to your dissertation committee as proof of authorization.

Your project is of great interest to the State of Alaska's DHSS, Division of Behavioral Health, section of Prevention and Early Intervention. We are looking forward to receiving a copy of the research study and reviewing its findings. Thank you for developing a research study that will support our efforts of preventing FASD in Alaska.

Sincerely,

L. Diane Casto

L. Diane Casto
Manager, DHSS, Behavioral Health
Prevention and Early Intervention Services

Appendix F

University of Alaska Permission to Use Archival Data

UAA UNIVERSITY of ALASKA ANCHORAGE
Behavioral Health Research & Services (BHRS)

November 9, 2008

Sarah L. Dewane, M.S., LPA
9138 Granite Place
Anchorage, Alaska 99507

Dear Ms. Dewane:

Thank you for your request to utilize the BHRS 2006 KABB Survey (see BHRS, 2007) dataset for purposes of your doctoral dissertation in the Ph.D. Program in Clinical-Community Psychology. After having reviewed your request, we have decided that this project is worthwhile and we are granting you permission to use the dataset for your stated purposes.

Permission is granted with the understanding that the data will not be not removed from the BHRS premises (physical or electronic) and that all data analyses will be conducted from the BHRS research offices at 42nd and Dale Street. It is also understood that the BHRS Co-Directors will have opportunity to review and comment upon all manuscripts that will be developed based upon these data, including your doctoral dissertation. Finally, it is understood that you have also secured permission from Diane Casto, Manager of Prevention & Early Intervention Services, Division of Behavioral Health, Department of Health and Social Service, State of Alaska, to use this dataset, as the original project was a collaborative effort.

Please keep me posted on the progress of your work and let me know if you need any assistance. Good luck to you with your dissertation – you have chosen an important topic and BHRS is honored to be able to contribute valuable data.

Best wishes,

Mark E. Johnson, Ph.D.

Cc: Virginia Mongeau, BHRS Data Manager
Marcine Mullen, BHRS Business Manager

Appendix G

Phase One Internal Review Board Approval Letters

UAA UNIVERSITY *of* ALASKA ANCHORAGE
Office of Research and Graduate Studies

December 23, 2008

Sarah Dewane, MS, LPA
9138 Granite Place
Anchorage, Alaska 99507

Dear Ms. Dewane:

Your Institutional Review Board (IRB) proposal entitled *Medical Providers' Perceptions about Fetal Alcohol spectrum Disorders in Alaska* meets the U.S. Department of Health and Human Services requirements for the protection of human research subjects (45 CFR 46 as amended/revised) as being exempt from full Board review. In keeping with the usual policies and procedures of the IRB, your research project is approved.

Therefore, you have permission to begin data collection for your study. If this study goes beyond one year from the date of this submission, you will need to submit a Progress Report (see http://www.uaa.alaska.edu/research/ric/irb/documents.cfm) for approval to continue the research and a Final Report submitted at the end of the project.

Please report promptly proposed changes in the research protocol for IRB review and approval.

On behalf of the Board, I want to extend my best wishes to you for success in accomplishing the objectives of your proposed study.

Sincerely,

Joanne K. Thordarson, M.S.
Research Compliance Administrator
Institutional Review Board

cc: Dr. Christiane Brems, Behavioral Health Research and Services
Dean James Liszka, College of Arts and Sciences

UAA UNIVERSITY *of* ALASKA ANCHORAGE

Office of Research and Graduate Studies

February 12, 2010

Sarah Dewane
9138 Granite Place
Anchorage, Alaska 99507

Dear Ms. Dewane:

This letter is in response to your request for continued Institutional Review Board (IRB) approval of your research project entitled *Medical Providers' Perceptions about Fetal Alcohol Spectrum Disorders.*

This project was originally reviewed by the IRB in December 2008. Your progress report states that you have had no problems with data collection, there are no changes to your protocols, and you would like an extension of IRB approval. Your request is hereby granted.

Should data collection extend beyond one year from the date of this letter, please submit another Progress Report for continuation of IRB approval or a Final Report after you have completed your project. These forms are available at http://www.uaa.alaska.edu/research/ric/irb/documents.cfm.

On behalf of the entire Board, I wish you continued success with your study.

Sincerely,

Dianne Toebe

Dr. Dianne Toebe
Co-Chair, UAA Institutional Review Board

cc: Dr. Christiane Brems, Center for Behavioral Health Research and Services
Dean James Liszka, College of Arts and Sciences

Appendix H

Phase Two Internal Review Board Approval Letter

UAA UNIVERSITY of ALASKA ANCHORAGE

Office of Research and Graduate Studies

August 3, 2009

Sarah Dewane, M.S., L.P.A.
9138 Granite Place
Anchorage, Alaska 99507

Dear Ms. Dewane:

Your proposal entitled *Phase Two: Medical Providers' Perceptions about Fetal Alcohol spectrum Disorders in Alaska* received an expedited review and was granted approval with revisions. Thank you for a copy of these revisions. Therefore, in keeping with the usual policies and procedures of the UAA Institutional Review Board, your proposal is judged as fully satisfying the U.S. Department of Health and Human Services requirements for the protection of human research subjects (45 CFR 46 as amended/revised). This constitutes approval for you to conduct the study.

This approval is in effect for one year. If the study extends beyond a year from the date of this submission, you are required to submit a progress report and to request continuing approval of your project from the Board. At the conclusion of your research, submit the required final report to the IRB. These report forms are available at the IRB website at http://www.uaa.alaska.edu/research/ric/irb/documents.cfm.

Please report promptly proposed changes in the research protocol for IRB review and approval. Also, report to the IRB any injuries or other unanticipated or adverse events involving risks or harms to human research subjects or others.

On behalf of the Board, I wish to extend my best wishes for success in accomplishing your objectives.

Sincerely,

Dianne Toebe

Dr. Dianne Toebe
Co-Chair, Institutional Review Board

cc: Dr. Christiane Brems, Center for Behavioral Health Research and Services
Dean James Liszka, College of Arts and Sciences